A STUDY OF THE SEVERITY OF DISABILITY AND NUTRITIONAL STATUS OF PEOPLE WITH DISABILITIES AND THE QUALITY OF LIFE AMONG PEOPLE WITH PHYSICAL DISABILITIES AND PRIMARY CAREGIVERS OF PEOPLE WITH DISABILITIES IN KANIYAMBADI BLOCK

DISSERTATION SUBMITTED IN PARTIAL FULFILLMENT OF THE REQUIREMENT OF THE TAMILNADU DR. M.G.R MEDICAL UNIVERSITY, CHENNAI, FOR THE DEGREE OF MD BRANCH-XV (COMMUNITY MEDICINE) EXAMINATION TO BE HELD IN APRIL, 2015

CERTIFICATE

This is to certify that "A study of the severity of disability and nutritional status of people with disabilities and quality of life among people with physical disabilities and primary caregivers of people with disabilities in Kaniyambadi block" is a bona fide work of Dr. Nancy Angeline G in partial fulfillment of the requirements for the M. D Community Medicine examination (Branch-XV) of the Tamilnadu Dr. M.G.R Medical University, Chennai, to be held in April, 2015.

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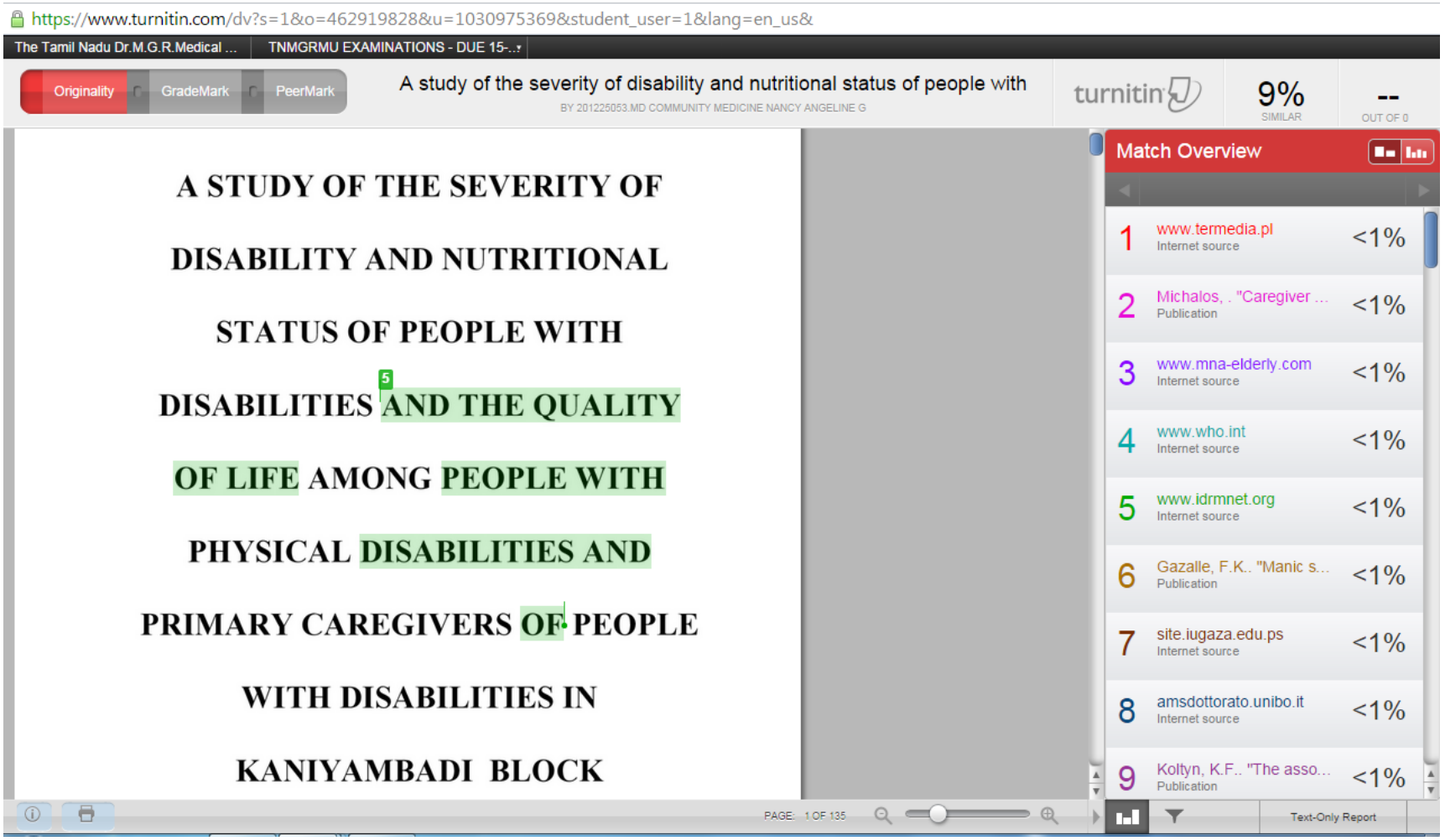

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ACRONYMS

ADL – Activities of Daily Living

AOR – Adjusted Odds Ratio

BMI – Body Mass Index

CC – Calf circumference

CHAD – Community Health And Development

CI - Confidence interval

CMC - Christian Medical College

EQ5D – Euroqol

ICC – Interclass Correlation Coefficient

ICF – International Classification of Functioning, disability and health

ICIDH - International Classification of Impairment, Disability and Handicap

IRB – Institutional Review Board

IRT – Item Response Theory

MAC – Mid Arm Circumference

MNA – Mini Nutritional Assessment

NSSO – National Sample Survey Organization

PROs – Patient Reported Outcomes

PTCHW – Part Time Community Health Worker

PWD – People With Disabilities act

QALY – Quality Adjusted Life Years

QLI – Quality of Life Index

QOL – Quality Of Life

SES – Socio Economic Status

UPIAS – The Union of the Physically Impaired Against Segregation

UN – United Nations

WHO – World Health Organization

WHO DAS 2.0 – World Health Organization Disability Assessment Schedule 2.0

WHO QOL-BREF – World Health Organization Quality of life Brief form

INDEX OF TABLES AND FIGURES

TABLE OF CONTENTS

ABSTRACT

Title: A study of the severity of disability and nutritional status of people with disabilities and quality of life among people with physical disabilities and primary caregivers of people with disabilities in Kaniyambadi block

Department: Community Health

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Degree and subject: M.D Community Medicine

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BACKGROUND:

Disability is a complex, multidimensional concept which affects all domains of life. Caregivers of people with disabilities face strains that influence their health and quality of life. Our study aims to assess the quality of life of people with disabilities and their caregivers. Severity of disability and nutritional status of people with disabilities was also assessed.

METHODS:

A cross-sectional study was done among 300 persons with disabilities and 300 primary caregivers. Participants with disabilties were administered WHO QOL-BREF, WHO DAS, ICF and MNA scale. Primary caregivers were administered WHO QOL-BREF. Prevalence of poor quality of life was assessed. Chisquare tests and odds ratios were calculated for factors affecting the quality of life and regression analysis was done to adjust for confounders. Two focus group discussions were conducted, one among the persons with disabilities and another among the primary caregivers to complement the findings of the quantitative part of the study.

RESULTS:

Among the 203 people with physical disabilities aged 18 years and above, 37.5% self rated their quality of life as poor. Factors which were significantly associated with poor quality of life in physical domain among them were non congenital causes of disability (AOR 3.025, 1.086-8.425) and severe disability (DAS score ≥45.21) (AOR 3.319, 1.585 – 6.948). Being single (AOR 3.253, 95% CI 1.474-7.181) and lower socio-economic status (AOR 4.092, 1.55-10.804) were significantly associated with poor quality of life in social domain of the people with physical disabilities. Being unemployed (AOR 2.404, 95% CI 1.181-4.894) was significantly associated with environmental domain of quality of life people with them. Among the 300 primary caregivers of people with disabilities, 25.7% reported poor quality of life. Caregiver being elderly (AOR1.764, 95% CI 1.007–3.088) and severe disability (AOR2.042, 95% CI 1.258-3.314) were associated with poor quality of life in physical domain among the caregivers. Caregiver being a parent or child (AOR1.804, 95% CI 1.075-3.027) and lower socio-economic status (AOR 2.076, 95% CI 1.64-3.705) were associated with poor quality of life in psychological domain and female caregivers (AOR 4.317, 95% CI 2.005-9.294) were significantly associated with poor quality of life in social domain. Among the persons with disabilities 60% were either malnourished or were at risk for malnutrition. Being single (AOR 1.831, 95% CI 1.013-3.311), having more than one disability (AOR 2.127, 95% CI 1.093-4.136) and severe disability (AOR 6.106, 95% CI 3.194-11.67) were significantly associated with malnutrition and being at risk for malnutrition.

CONCLUSIONS:

The quality of life of persons with disabilities and their caregivers is by and large poor and socio-economic and employment status are factors which can improve their quality of life. More than half of the persons with disabilities are either at risk of malnutrition or malnourished. Nutritional assessment and intervention should be an essential part of rehabilitation.

KEY WORDS: Disability, Persons with disabilties, Quality of life, Primary caregivers, Nutritional status, Severity of disability.

1. INTRODUCTION

Most individuals would have suffered from disability, be it temporary or permanent, either in younger, middle or old age. Many families have atleast one member with disability and any family member would have had a caregiving experience at some point in the ir lives. Disability has become a problem worldwide since most of the population is ageing (1). Increasing number of persons with disabilities worldwide have characterized the world's most underprivileged groups who have been least included in any developmental plan and goals internationally. Developing nations represent 80% of the persons with disabilities (2). Disability is considered as an evolving notion. It is not ascribed to a particular person but results from an inter-relationship between the environment and the society (3).

A person with disability has a different view of his health, the society, the environment and the world. This draws a distinction from a normal person's view point. Quality of life of a person with disability cannot be assessed only by health related quality of life since disability affects social, psychological and environemntal domains of a person's quality of life. In developed countries, people with disabilities have been observed to have good quality of life despite the adverse health condition (4). The same results cannot be expected in developing nations since the employment opportunities, educational attainment and expenditure pattern are different from developed nations. In developing nations more people with disabilities are pushed into poverty due to their health status (5). Studying the quality of life among people with disabilities is important since discrimination, negative outlook on the disabilities and ambivalence in attitude towards them arises due to the belief that they have poor quality of life (6). Poor quality of life among the people with disabilities reflects the adverse environmental conditions,

transport and housing facilities, education and employment opportunities (7). Obesity and overweight among the people with disabilities and inadequate diet are demonstrated in multiple studies (8,9) but there is dearth of studies on malnutrition among the people with disability.

In the Indian scenario, caregivers are usually family members who provide care to the person with disability. Caregiver mental and physical wellbeing is forgotten due to the focus on the person with disability.

However, caregivers undergo significant turmoil during the process of caregiving such as change in occupational and social aspects of their lives, unstable family income, stress, feeling burdened and depression. Reduced participaion in community activities is also noted among caregivers due to their caregiving role. Some of their cargiving roles includes difficult tasks which drains them emotionally and physically (10). Cognitive impairment and psychiatric diseases in the persons receiving care produces more burnout in the caregivers (11). Significantly lower quality of life has been observed among caregivers of people with disabilities as compared to the general population. Greater caregiver burden implies poorer quality of life (12).

Public health views disability to be as significant as mortality. Present advances in health care facilities have reduced mortality and promoted longevity, however non communicable diseases, disability and geriatric diseases are emerging problems. For effective public health planning and setting priorities in a population, measuring health and disability is important. Since disability is a complex phenomenon, it is equally complicated to measure it. Disability should not be seen as only a health problem but as an intricate relationship between self, environment and society. It is essential to measure

disability to know the patient's needs, to planning, policy making, allocate resources and to measure outcomes (13).

Available data on disability worldwide is said to be insufficient . Most countries depend only on surveys and censuses for their data on disability (14). Studies on disability is scarce in developing nations especially in India (15). There is a need to conduct research in this area. This study proposes to assess the quality of life of people with physical disabilities and primary caregivers of people with disabilities, and the nutritional status and severity of disability of the people with disabilities in a rural south Indian block.

2. OBJECTIVES

1. To assess the quality of life of people with physical disabilities aged 18 and above in Kaniyambadi block.

2. To assess the severity of disability and nutritional status among the people with both physical and mental disabilities aged 18 years and above in Kaniyambadi block.

3. To assess the quality of life of primary care givers of people with disabilities in Kaniyambadi block

3. REVIEW OF LITERATURE

Disability has never been in the limelight in the world of public health. However, off late there has been growing concern about the mounting population with disability through out the world. In present days due to effective public health interventions and medical research many people are living longer. Many individuals who would have previously died from injuries, impairments and congenital defects are continuing to survive with impairments (16). The people with disability often remain as minorities and are invisible in the society. Public health prevents disabilities but the health and welfare of disabled are relatively new concepts. In recent years there has been an increase in disability studies most of being cross sectional in nature and have revealed the gaps in health care and inequality experienced by the the people with disabilites (17).

3.1 DEFINITION OF DISABILITY

Defining disability is considered highly controversial because the understanding of disability is changing over the years (2). The terms used for people with disabilties in the past are now considered offensive and euphemism has changed the way they were being called. Terms such as moron, imbeclie, idiot, feeble minded and cretin were replaced by the psychiatry term 'Retarded'(3). In the pre industrial era, the people with physical disabilities were called crippled, handicapped and lame. These were considered politically incorrect and newer terms such as physically challenged and disabled came into being (20).

The WHO in 1976 defined impairment as 'any loss or abnormality of psychological, physiological or anatomical structure or function', disability as 'any limitation or deficiency (resulting from an impairment) of capability to carry out an activity in the

manner or within the range considered normal for a human being' and handicap as 'any difficulty (for a given individual) resulting from an impairment or a disability, that limits or prevents the fulfilment of a role that is normal (based on age, sex and social and cultural factors) for that individual' (21).

In 2014 WHO defined disability as 'a blanket term which includes impairments, activity limitations, and participation restrictions. An impairment is a defect in body function or structure; an activity limitation is the problem faced by an individual in executing a task or action; while participation restriction is a difficulty encountered by an individual in engagement in life' (6). 'The Americans with disabilites act 1990' defines a person with disability as one who has an impairment which considerably impairs activities of life (7). In India definition for disability is derived from the Persons with Disabilities (equal opportunities, protection of rights and full participation) act, 1995. It defines disability as 40 or more percent of disability certified by medical personnel. Disability in this act includes the following impairments (24): 1) **Blindness**: It includes complete absence of vision, visual acuity not more than 6/60 in the better eye even with correction, restriction in field of vision with 20 degrees or worse. 2) **Low vision**: impairment in vision even after treatment or correction. 3) **Cured cases of Leprosy**: It includes three categories of cases. Anasthesia paresis of eyes and lids, with deformity and paresis but able to work, severe deformity that hinders any economical activity. 4) **Hearing Impaired**: Deficit of 60 decibels or more in the better ear. 5) **Locomotor impaired**: Any form of cerebral palsy, or any limitation in movement of limbs. 6) **Mental retardation**: Partial mental development and below normal intelligence.7) **Mental illness:** Psychiatric conditions other than Mental retardation. During Census 2001 it was realized that these definitions were complicated and not simple enough for use in census. Therefore straightforward definitions for 1) seeing, 2) speech, 3) hearing, 4) movement, and 5) mental were put

forth. The National Sample Survey Organization(NSSO) survey of the disabled persons 1981 used only 3 types of disability for its definition of disability namely visual, hearing and speech and locomotor (25).

3.2 MODELS OF DISABILITY

In attempting to define disability it is important to know the models of disability. Disability is a multifaceted complex condition which continues to interest the researchers who are studying it. The important models put forward to explain disability are (26,27): moral or religious model, medical model, social model, rehabilitative model, nagi's model and International Classification of Functioning, disability and health (ICF) model

3.21 MORAL OR RELIGIOUS MODEL

It is the oldest model for disability and thankfully is disappearing from many countries. According to this model, disability is the result of the sins commited by self or some family member. Diseases such as seizure or schizophrenia were considered as divine possession or devil's possession in various communities. Several religions consider disability a result of God's dissatisfaction with a person. Exorcism was considered as cure for psychiatric illnessess and the people with disabilities were identified as the needy requiring merciful care by some religions.This model is crticised for causing social ostracism among the people with disabilities and their family. Guilt, shame and loathing of self form this model (27,28).

3.22 MEDICAL MODEL

The medical model for disability gathered momentum around 19^{th} century. To date, this model continues to be followed. The people with disabilities are at the mercy of physicians to be healed, to devise policies and the society had no role in the people with disabilities's lives (27). Also called 'Personal tragedy model', this often causes the people with disabilities to feel sorrow about their physical condition. The role of society and

physical environment in the people with disabilties's lives is forgotten in this model (29). The medical model revolves only around the person with disability devoid of external factors. Disability is considered as a disease and the person with disability is assumed to fill the role of sick. This model has the greatest impact on how disability is being viewed. Cure and eugenics were approaches for this model (30).

3.23 SOCIAL MODEL OF DISABILITY

One of the oldest social models of disability was described by Jane and Lucien Hanks in 1948. It explains the social model in non western countries. Some people with disabilities were excluded from societies and were even considered as dangerous. Economically the people with disabilities were considered liable since they rob considerable amount of capital which could be used for productive purposes (31). In the present days it is a favourable model among people with disabilities and sociologists alike since it makes the society more involved with disability (32). The Union of the Physically Impaired Against Segregation(UPIAS) British model of disability states that the society majorly makes a physically impaired person as disabled by means of seperating them from main stream and preventing them from actively participating in activities (33). Social model is concerned with hurdles removal, social equity and autonomous living. Rights of the persons with disabilities and activism require the social model for their functioning. It's a realistic instrument which unshackles the disabled from the barriers they face. It increases the self worth of the individual with disability (34).

3.24 RIGHTS BASED MODEL OF DISABILITY

That the persons with disability cannot function and participate normally cannot be the consequence of their impairment alone; the society and the environmental factors such as construct of buildings also are to be blamed. The rights based model of disability was the brain child of many disability activists. The Australian disability discrimination act 1992

is one such rights based legislation. In 1993 the first European disabled people's parliament was conducted which warranted against discrimination, societial, environmental barriers and promises full participation of the people with disabilities in the society (35,36). The rights of the person with disability has been devised by United Nations (UN). After the International Year of Disabled Persons, 1981 the World programme of Action for the person with disability was developed by General assembly of UN. It highlighted the rights of the persons with disabilties as equal opportunities as compared to normal people, same share in conditions of living and economic development. In the UN decade of persons with disabilities, it was suggested that the states should take adequate steps to remove hurdles which prevent the people with disabilities from implementing their rights and freedom and encourage them to participate in social and economical activities. The persons with disabilities are citizens like any normal person and they should enjoy equal rights and assistance in education, occupation and medical services. Equal rights and obligations should make sure that the person with disability perform in societies as normal members (37). The Persons With Disabilites act 1995 (Equal opportunities, protection of rights and full participation) was passed for Asia and Pacific regions, for Governments to adopt special measures for prevention of disabilities, social, educational development of the people with disabilities, supply of aides, access to places for them and disability research (38).

3.25 REHABILITATIVE MODEL

After the first world war, millions of veterans returned home with disabilities and the concept of eugenics which involved isolating, sterilizing or even killing them in gas camps by the Nazis, was challenged and the home coming heroes of the war had to be received back into the society. Remarkable flourishment in the fields of prosthetics and surgery for rehabilitation was witnessed. Exercise regimens and occupations which could

be done by the people with disabilities were encouraged among the veterans (39). Thus the rehabilitative model is the sister model of medical model but with promising benefits for the people with disabilities. It implies that all people with disabilities need special training by therapists who will ensure that the persons with disabilities become functional and go back to the communities without the role of sick. Many of the disablities can never be cured but the people with disabilities can be trained to function almost normally by rehabilitation (27).

3.26 NAGI'S MODEL OF DISABILITY

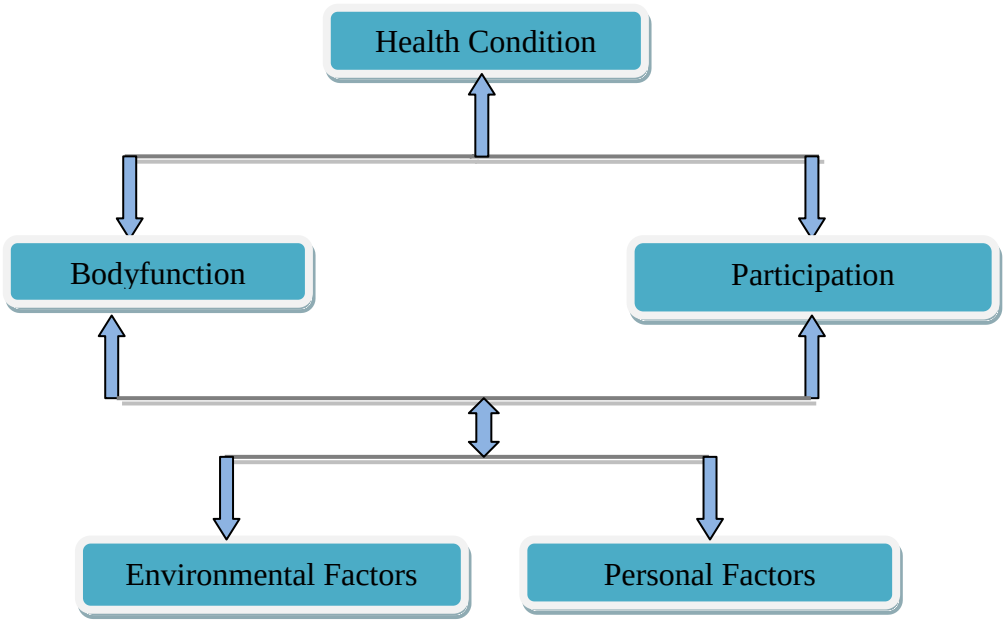
In 1991 Nagi put forth this model of disability which focuses more on the cultural and environmental aspects of disability. A woman who lives in a community where women do not go to work, could not go to work would not be considered as disabled even if she were physically unable to work due to a disability. On the other hand, a woman lives in a community where women regularly go for work will be considered as disabled. This model stresses more on the interaction between the individual, society, physical environment, cultural beliefs and political situations than the disability as such (40).

3.27 INTERNATIONAL CLASSIFICATION OF FUNCTIONING, DISABILITY AND HEALTH

International Classification of Functioning, disability and health (ICF) started to get used in 2001. It was devised by WHO. It is a versatile tool which classifies the disabilities, identifies the environment and health conditions associated with disability. It can be used by health and other sectors related to disability. It integrates the existing important models of disability. It is adaptable for various countries and ethnicities. Unlike older models it is based on scientific evidence and it forms the lingua franca among health workers, scientists, general population, the disabled and the legislative bodies. It is recognized as one of United nations social classification. It is also being utilized for scrutinizing the

aspects of UN convention on the Rights of persons with Disabilities and also other international and country wise policies. The ICF associates functioning and disability with functions and structure of body, activity and participation of people and environmental factors which also play a role in disability (41). ICF does not detach health from disability unlike conventional models. However on careful examination the domains that define health and disability are infact similar and the manifesation is only varied. ICF is the latest and a concept centered model which makes disability universal and understandably simple. It does not rely only on medical aspects of disability but also psychological social, cultural and environmental effects on an individual with disability. It is very different from its fore runner ICIDH (International Classification of Impairment, Disability and Handicap) because in ICIDH disability is largely due to the physical impairment. ICF model is used in disability surveys, censuses, data analysis, development and monitoring of national programmes. (42)**.**

Figure 3.1 Interactions between the components of ICF



Source: ICF,WHO 2001:1. Available from ICF: An overview. Introducing the ICF. Available from http://www.wcpt.org/sites/wcpt.org/files/files/GH-ICF_overview_FINAL_for_WHO.pdf

Table 3.1 ICF: Components and domains

BODY FUNCTIONS	ACTIVITIES AND PARTICIPATION
1. Mental functions **2.** Sensory function and pain **3.** Voice and speech **4.** Functions of the cardiovascular, **5.** haematological, immunological and respiratory systems **6.** Functions of the digestive, metabolic and endocrine system **7.** Genitourinary and reproductive functions **8.** Neuromusculoskeletal and functions related to movements **9.** Functions of the skin and the related systems	**1.** Learning and applying knowledge **2.** General tasks and demands **3.** Communication **4.** Mobility **5.** Selfcare **6.** Domestic life **7.** Interpersonal interactions and relationships **8.** Major life areas **9.** Community, social and civic areas
BODY STRUCTURE	**ENVIRONMENTAL FACTORS**
1. The structure of the nervous system **2.** Eye, ear and related structures **3.** Structures involved in speech, voice **4.** Structures of cardiological, immunological and respiratory system **5.** Structures related to digestive, metabolic and endocrine systems **6.** Structures related to genitourinary and reproductive system **7.** Structures related to movement **8.** Skin and related structures	**1.** Products and technology **2.** Natrual environment and human made changes to it **3.** Relationship and support **4.** Attitudes **5.** Services, systems and policies

Source: WHO 2001 : 29-30. Available from http://www.wcpt.org/sites/wcpt.org/files/files/GH-ICF_overview_FINAL_for_WHO.pdf

3.3 MAGNITUDE OF THE PROBLEM

The world health survey conducted among 69 countries showed the prevalence of disability among adults aged 18 years and above to be 15.6%. This corresponds to a total number of more than one billion. The prevalence ranges can be as high as 18.0% in lower income countries and 11.8% in the higher income countries. In all the countries vulnerable groups such as women, poor and the elderly suffer the most from disability (8).

In the survey of the income and program participation done in the United states in 2005 the prevalence of disability was found to be 21.8% (9). In the United Kingdom there are 11 million adults with disability and 770,000 children with disability (45). The 2012 Canadian disability survey reports that 11% adults have either pain, mobility or flexibility disability types and 3.9% of them reported mental disability (10). Among the younger age group mental disability was more common at about 2.2% but 12.7% of the older reported pain as the most common disability. Very severe disability constituted 20.6% of those who were surveyed.

According to Indian Census, 21 million people have disability accounting for 2.1% of the total population. Of these 12.6 million are males and 9.3 million are females. The states with largest amount of people with disabilities in descending order are Uttar Pradesh, Bihar, West Bengal, Tamilnadu and Maharashtra. A total of 1.6 million people with disabilities live in Tamilnadu. It is distinct from other states in that the women outnumber the men in disabilities (47). According to the National sample survey 2002 prevalence of disablity was 1.85% in rural areas and 1.5% in urban areas. The most common disability was locomotor followed by hearing (48). In a study done among rural geriatric population in Tamilnadu visual disability was found to be the most common cause of functional limitation accounting for 56% of the population, 10% of the study population had hearing

disability and 4% speech disability. Greater than two thirds of the elderly had one functional limitation and 22% had atleast one restricted activity of daily living (49).

In 2004 a cross sectional study in Karnataka found the prevalence of disability to be 6.3%. Persons with multiple disabilities contributed to 80% of all disabilities (50). In a community based study done in rural parts of Karnataka the prevalence of mental disability was observed to be 2.3% and the prevalence was higher among elderly and illiterate (51). In Kaniyambadi block, Vellore district of Tamilnadu the prevalence of disability was found to be 6.7%(52). In another study done in rural part of Tamilnadu prevalence of disability was found to be 0.85% (53) .The prevalence of disability varies from country to country due to reasons such as different definitions for disability, different methodology and quality of studies (54). In a bibliographic search done by the WHO the prevalence of indicators of impairments was 0.1 - 92% , disability was 3.6 – 66%, handicap 0.6 – 56% and low quality of life 1.8 – 26% (55).

3.4 DISABILITY IN DEVELOPING AND DEVELOPED NATIONS

In developed nations the prevalence of disability appears to be high due to various factors such as excellent medical, elderly care, medical research and rehabilitation services (54). More over they tend to collect data through surveys which provide plentiful data on disability as compared to censuses (56). Types and prevalence of disability in a country also depends upon the pattern of chronic diseases, conflicts, injuries, substance abuse and disasters (57). There is paucity of data on disability in general and more so in the developing and under developed countries (58). Available data is considered to be of poor quality(59). To make matters worse 71% of the people with disabilities comprises of people who have invisible disabilities like learning and cognitive disability (60).

In many developing nations people with disabilities are concealed from general public, segregated and indiscriminated. Many infants are killed because they are born with

disabilies. Abuse is rampant. These violations of human rights happen due to cultural beliefs and attitudes. Therefore the disability picture in developing nations is incomparable with that of the developed nation (61).

In Bangladesh Titumir and Hossain reported in 2005 the prevalence of disability as 5.6% and that the prevalence was less in areas where disability services were adequate (62). Even in developed countries despite functioning programs for the people with disabilites, the earnings of the people with disabilities are not proportional to their normal peers. However, the situation is worse in developing countries. While in developed countries accidents and conflicts are growing concerns of cause of disability, in developing countries infectious disease, maternal, perinatal conditions, injuries and childhood disability, which could be prevented or treated through rehabilitation are the reasons for disability (63).

3.5 MEASURING DISABILITY

The objectives of measuring disability includes, assessing the general health of the population, devising disability benefit policies, measuring needs of the disabled community, studying the impact of disability on employment and impact of disability on quality of life (64).

Measurement of disability is plagued by multiple issues as diverse as the problem of disability itself. Majority of the tools used are non standardised and estimates measured between countries tend to be difficult to compare (63). Measuring disability in surveys is a difficult task for the interviewers to make decisions on whether self or other person is disabled or not. Disability as such poses numerous methodological problems, in trying to measure it. Problems include swerving course of the disabling conditions overtime and self-proxy disagreements in judging whether an individual is having disability or not. The

same question during a survey, when asked in a different manner produces different prevalences of disability (65).

Every disability has a different type of medical, social and rehabilitative need to be addressed and it is important that the measurement of disability is done. At first, many people find the term disability to be insulting and may refuse to identify themselves as one. When asked "Do you have disability?" the shame around disability and mental status of the individual being asked are to be considered. Relevent questions that might be asked are "Do you have limitation in performing a particular activity?". However, in countries which depend upon censuses for data on disability, such questions might be practically difficult to administer since censuses are conducted over long periods and done among the entire population (54). It has been studied that simplifying questions on disability will improve the quality of results but its effect on rates of disability is not known. When attempting to measure disability both yes or no questions and five point scale are prone to self-proxy differences and inconsistency (65). There is insufficient data on how the government sample surveys and census data on disability is collected in India. The possible impact on types of disabilities measured also are unknown. Problems specific to India in measuring disability include stigma, accuracy in diagnosing impairments especially in the elderly, overlooking of mild impairments as normal part of life or ageing The census and the National Sample Survey (NSS) have significant differences in their definitions of impairments. This explains their differnce in estimates of disability in the country. The NSS definitions are more exhaustive and tend to produce higher prevalence (66).

3.6 ASSESSMENT OF DISABILITY

Worldwide disability assessment is done under the following conditions - to identify patients's needs, To confirm the level of care patient needs, to assess the effect of the

disaese, to ascertain if the patient requires benefits, to assess the working capacity of a person and social participation of a patient. Disability assessment is not only relevant in clinical settings but also in policy making and programming. It is useful for calculating outcomes, effeciency of a treatment/ intervention and allotment of resources (13).

In India, ssessment of disability is done for several reasons, A physician might be called to the court to testify a person as disabled, for issuing disability certificate and for assessing disability in clinical areas. Disability assessment may be done to issue ccertificates, tax deductions, travel charge concessions, priority in employment, for allocate awards, compensations and admittance into various educational courses. Some Acts in India which provide compensation in occurances of disability are -Work man's compensation Act, Motor vehicle Act, Employment State Insurance Act, Railways Act, civil aviation Act and quantum damage Act. In India, disability assessment is done for issuing disability certificates, railway concession certificates, employment related certifiates and driving certificates for the people with disabilities (67–69). The social security benefits offered to a person with disability after disability assessment in India include reservation in government services, priority in employment, pension under Employees's provident funs and Miscelleneous Provisions Act 1952, medical benefits under Employee's State Insurance Act 1948, benefits mentioned in Workmen's Compensation Act 1923, Schools of mentally challenged children and assistance programmes. The three Acts mentioned here are related only to employed persons (70). The Indira Gandhi National Disability Pension Scheme, a component of National Social Assistance Programme (NSAP), provides Rs. 300 per month to individuals living below poverty line and aged 18 – 79 years with severe or multiple disabilities. It has been planned to increase it to a total of Rs. 1000 per month and to reduce the level of disability from80% to 40% (71). In the state of Tamil Nadu, destitute pension is given for

physically handicapped persons with more than 50% disability and any blindness. They are entitled for a total of Rs. 400 per month (72).

3.61 TOOLS FOR DISABILITY ASSESSMENT

3.611 WHO DAS 2.0

This is a generic tool which can be used for both people with disabilities and people with out disabilities such as any diseased. WHO DAS 2.0 does not only assess disability but also diseases, injuries, psychiatric conditions and dependence on alcohol or drugs. It cannot distinguish between physical and mental disabling conditions.

The tool takes only 5 to 20 minutes to administer. Simple hand scoring of each domains can be done in busy clinical settings. Complex weighted scoring instructions are based on Item Response Theory (IRT). Conceptual relationship between ICF and DAS can be observed. It is also appropriate for different cultures.

The domains covered in WHO DAS 2.0 are, cognition and understanding, movement, personal care, social relationships, household and work/school related activities and community participation (73).

PSYCHOMETRIC PROPERTIES OF WHO DAS 2.0

In assessment of a measurement tool, validity and reliability are two essential components. Validity refers to the level at which the instrument measures what it is expected to measure. Reliability indicates the capacity of the instrument to measure consistently. Internal consistency refers to the ability of the tool to measure the same notion throughout the questionnaire, also referred to as inter-relatedness. Internal consistency is measured by Cronbach's alpha and the acceptable range is 0.70 – 0.95 (74).

In a study done among 3615 depressed patients, WHO DAS was administered and to study its effectiveness a non parametric Item Response Theory (IRT) was used. IRT is a

powerful tool which provides specific information on item functioning. It is composed of a parametric and a non parametric model which explain the probability of a particular answer to a scale as a function of the individual's trait. WHO DAS distinguished various levels of disability well. Non parametric IRT analyses done in this study revealed that the WHO DAS 2.0 items and choices distinguished well among various levels of disability and was non partial towards gender (75). In another multi centric study done in Europe among 1119 participants with different chronic conditions, Cronbach's alpha ranged from 0.77 for self care domain and 0.98 for work/school domain. A reasonably high ceiling effect was observed in all domains, particularly in the self care domain (53.6%). The questionnaire correlated moderately with SF- 36. There was a statistically difference observed between working and non working population's total scores (76).

VALIDITY

When WHO DAS was administered along with other instruments such as London Handicap scale, SF-36, Functional independence measure, WHO QOL 100 and WHO QOL BREF, correlation coefficients for similar domains were highest. For other domains the correlation coefficient was between 0.45 – 0.65

CROSS CULTURAL COMPATABILITY

WHO DAS was developed over 19 countries. Cross cultural applicability study was done by means of qualitative methods and it was concluded that the instrument was applicable universally (77).

TEST RETEST RELIABILITY AND INTERNAL CONSISTENCY

Overall cronbach's value is very high for WHO DAS 0.98. Test retest reliability had an intra class coefficient of 0.98 (13).

3.7 GRADING OF DISABILITY

WHO introduced ‘disability classification’ for leprosy in 1960 and revised it in 1970 and 1988. The aim of grading was to assess any setbacks in case finding and to prevent disabilities. Grading was done only for eyes, hands and feet. The grades given were 0,1,2 scores and the corresponing degree of impairment was mentioned. This grading even though generated for leprosy, can be used for non leprosy cases also (78).

3.71 WHO GRADING SYSTEM

HANDS AND FEET

Grade 0 - No anaesthesia, no visible deformity or damage

Grade 1- Anaesthesia present, but no visible deformity or damage

Grade 2 - Visible deformity or damage present

EYES

Grade 0 - No eye problem due to leprosy; no evidence of visual loss

Grade 1- Eye problems due to leprosy present, but vision not severely affected as a result (vision: 6/60 or better; can count fingers at 6 metres).

Grade 2 - Severe visual impairment (vision worse than 6/60; inability to count fingers at 6 metres); it also includes lagophthalmos, iridocyclitis and corneal opacities (79).

RELIABILITY OF WHO DISABILITY GRADING

WHO disability grading has excellent reliability even if used by persons with little or no training in it. In a study done among testers who were not familiar with using WHO disability grading, the weighted kappa statistics ranged from 0.87 – 0.89 and 95% Confidence Interval (CI) was 0.73 – 1.0 for the top score and for the eye hand and foot score 0.90 – 0.96, 95% CI being 0.90 – 0.99. Even with little training and constrained knowledge a good level of reliability can be achieved (80). Similar results have been

produced in another setting where inter-tester reliability was measured by means of kappa statistics. A value of 0.89 (95% CI 0.84 - 0.94) was obtained for the maximum grade and for Eye, hand and foot score 0.97 (95% CI 0.96 – 0.98) was obtained. WHO disability grading can be done by both experienced and inexperienced hands (81).

3.8 DISABLING CONDITIONS

The global burden of diseases 2004 report mentions these as leading disabling conditions causing moderate and severe disability - hard of hearing, refractive errors, depression, cataract, unintentional injuries, osteoarthritis, alcohol dependence, asthma, coronary artery disease, psychiatric illnesses and cerebrovascular disease (82). Communicable disease, maternal, perinatal and nutritional causes together causes 43.9%; non communicable diseases 40.9%; trauma 15.1%; cancers 5.1%; psychiatric problems 10.5% and cardiac diseases 9.7% of Disability adjusted life years worldwide (83).

Factors causing disability can be broadly classified into genetic/hereditary, perinatal, preterm/ lowbirth weight, childhood injuries, infections and substance abuse (84). In the Survey Of Income And Program Participation (SIPP) done in the United States in 2005 the common disabling conditions identified are arthritis, rheumatic conditions (8.6 million affected), back and spine related conditions (7.6 million affected) and cardiac problem (3.0 million affected) (85). WHO identifies musculoskeletal conditions as the leading cause of disability worldwide. Musculoskeletal conditions include rheumatoid arthritis, osteoarthritis, osteoporosis, spinal conditions and trauma to limbs (86). The United Nations (UN) lists causes of disability to be congenital, maternal and perinatal causes, ignorance, illiteracy, poor housing facility, natural disasters, lack of good health services poor hygiene, malnutrition, road traffic accidents, work and sports related injuries, life style diseases, consanguinous marriage, substance abuse, ageing and infectious diseases. Factors which are of importance in the web of causation of disability are environmental

pollution, unethical scientific experiments, war and violence (87). In a study done in rural area of Tamilnadu common causes of disability which were identified were congenital 60.7% and accidents 20.7% (53).

3.9 TYPES OF DISABILITY

There are various types of disabilities affecting people at any time in their lives.

According to the ICIDH WHO 1981 the types of disabilities are behavioural disabilities, communication disabilities, disability in performing personal care, locomotor disability, disability in body proportion, disability in dexterity, situational and environmental disability and disability in a particular skill (21). The International Classification of functioning, disability and health (ICF), WHO 2001 brings the numerous types of impairments, disabilities and handicaps under one classification.

Disability has multiple facets and it is related to

1. Body function and structure. Impairment happens at this level
2. Activities – functioning gets affected and limitation of activity happens
3. Involvement in various aspects of life – participation restriction occurs
4. Environmental factors affects all the above factors and acts either as barriers or hindrances

ICF embraces social and medical models of disability. It is therefore superior to other types of classification. The ultimate stage of functioning is decided by the intermingling of body function impairment, environmental conditions and participation limitation (88). Various types of disabilities are mentioned in literature. Types of disabilities mentioned in the census India are visual disability at 48.5%, followed by locomotor 27.9%, mental 10.3%, speech 7.5% and hearing 5.8% (47). In rural Tamilnadu locomotor was common (44.2%) followed by psychiatric disorders (27.8%), hearing and speech (13.5%) and visual (10%) (53).

3.10 IMPACT OF DISABILITY ON THE INDIVIDUAL

Disability impacts social, economic, political, psychological aspects of a person's life. There are five phases in adjusting to a particular disability. They include initial shock, understanding of condition, being defensive, recognition of condition and finally adaptation. Our socities push a person with disability to take up the role of minority status. Their social identity is defaced and they are considered as less attractive, less efficient and this affects the individual's and family's economic status as well. Significant reduction of social contacts of a person with disability, reduced involvements in community activities and reduction in number of roles played by person can be observed as effects of disability on an individual (89). As compared to their non disabled peers, the people with disability have less savings and assets and receive lower level of education and earnings. Disability adversely affects labour supply. Inclination towards incentives has reduced the chances of employment in an individual with disability. Literature has failed to distinguish between limitation of activity and work capability. Disability can affect the employment status of an individual by means of the impairment which can adversely affect the work capacity or because of the difficulty in finding an employer who is willing to employ a person with disability. Technical and difficult jobs such as manoeuvring machinery, communication, complex works might not be undertaken by the person with disability. Additional tasks of any job such as travelling and entering inaccessible places might pose further risks to persons with disabilities (90).The higher socio-economic class is unlikely to be affected by disability as much as the lower class since the latter is more involved in occupations which demand heavy physical activities such as coal mining, load lifting and construction. Often the people with disabilities are left with jobs which are under paid and unskilled. The unemployed people with disabilities follow a of lack of self esteem and perishment routine. Unemployment is

important since the unemployed lose their social position in the society and sometimes experience what is referred to as social death (91). Higher the level of disability lesser the employment status of the individual. Despite legislations disability level is inversely related to employment and income status (92). Schemes on social security and medical benefits for the people with disabilites are not sufficiently upheld by current programs. Expenditure on social security schemes surpass the income genrerated through non income means for the government (93). In a study done in Karnataka half of the people with disabilities were found to be unemployed (50).

ASSESSMENT OF SOCIOECONOMIC STATUS

Socio Economic Status (SES) can be assessed using various scales.1) **B G Prasad classification** – this was developed in 1961 based on per capita monthly family income and number of family members. 2) **Pareek classification** is used in rural areas. It is constructed upon 9 features, namely, caste, occupation, education, social participation, amount of land owned, house type, farm power, owning of materials and total number of members in family. 3) **Modified Kuppusamy's scale** is used in urban settings. Of these Modified Kuppusamy's scale is widely used to assess the SES (94). Some important definitions in relation to SES are

Table 3.2 Definitions of different types of education

Illiterate	No formal education
Primary school	Till 5 th standard
Middle school	Till 8th standard
High school	Till 10 th standard
Higher secondary	Till 12th standard
Intermediate/ post high school diploma	Predegree and diploma after school
Graduate/ post graduate	BA / BSc / BCom (95).

Table 3.3 Definitions of different types of occupations

Un employed	Not involved in any type of employment or livelihood activity
Unskilled	Works involving simple tasks with very less or no experience and reasoning. This involves physical exertion and getting used to the environment of the work
Semiskilled	Involves work of defined agenda. Not much of reasoning and skills are required. Beedi work, hotel, construction, mason, fishing, sales, ragpicking, street vending and load lifters come under this group. Decision making is not a part of this work
Skilled	These works involve discipline and proficiency, freedom and judgement. A skilled worker like a tailor has good knowledge of his work.
Clerical, shopowner businessmen farm owner	These form a self explanatory separate group. They also includes Class III government service employees.
Semi profession	School teachers, Class I, II officers in government services are classified into this group
Profession	Doctors, advocates, chartered accountants and engineers form these group (95,96).

TYPE OF HOUSE

Hut: A single roomed house made up of kutcha or semipucca materials like mud, bamboo, grass, leaves, reeds, thatch or unburnt bricks.

Kutcha house: Walls and roof of the house will be made of non pucca material like bamboo, mud, grass, leaves, grass, reeds.

Mixed house: Cannot be classified as pucca or kutcha. Mixture of both materials is seen

Pucca house: Walls and roof made of pucca materials like cement, concrete, burnt bricks, stone, iron, timber, tiles, corrugated iron asbestos or cement sheet (97).

TYPES OF FAMILIES:

Nuclear: Consists of married couple and their children. They occupy the same dwelling place.

Joint/ exended : A number of married couples and their children live together. All the property is held in common. Senior male member is the head of the household (98).

3.11 IMPACT OF DISABILITY ON SOCIETY

The society has always rejected any deviation from normalcy and disability is no exception. In Neur, an african tribal culture, babies born bigger than normal size were thrown into river. Twins were considered as abnormal and killed at birth (99).

A person with physical disability are often found to have lost their social identity. They were socially less influential, despite being equally or more competant than the non disabled (100).

People with disability are hardly employed in technical, executive and administrative professions. Disabled population profile is so diverse that it is very difficult to define their employment requirements broadly. Due to options of flexibility, the people with disabilities prefer self employment and part time occupations. Inspite of having discrimination acts, discrimination is reported in work places (101). A study conducted in United States in 2000 revealed that disabled people are paid less not because of their impairments or competancy levels but because of prejudice (102).

Adding to the anguish of coping with their physical disability, the disabled also have to brave the response of the society to their appearance or behaviour. Communities generally perceive disabled people as disparaging typecasts, inferior in the society and reduced contribution to the society. The non disabled people often do not think twice before questioning the disabled on their condition, since it is accepted that the disabled can be treated with meagre respect and they are underprevileged. Such reactions

adversely affect the pschological well being of the individual restricting their participation. Disabled children are observed to have reduced self esteem. Such situations favours abuse, since the child is seen as defective(103). There is a dearth of studies on sexual abuse on disabled. Evidence proves that people with disabilities are at increased risk of sexual abuse. The vulnerability of the population exposes them to this social evil (104).

3.12 IMPACT OF DISABILITY ON FAMILIES

Four impacts of disability on children of families with disability mentioned in literature are acquisational, social, emotional and behavioural. In families of parents with mental illness children were obseved to have increased risk of psychiatric illness and psychiatric symptoms.

Much of the stigma associated with disability also affects the children. They are usually the acceptors of stigmatizing remarks and comments from the society. Emotional effects of a disability in the family arises due to caregiver role taken up by the children, maladaptation to the changing family dynamics and multiple responsibilities. Acute illness in the family can bring the family together and improve the security levels, but chronic illness and disability in particular can be emotionally draining (105).

Families of children with disability were observed to be spending twice as compared to that of normal children. At the same time, disabled children report that they receive only a third of what they demanded. Many children are made to believe by their parents that they are as good as other families economically even though their incomes are below national averages. All parents labour to do their best for their children but parents of disabled children are concerned that they are not adequately spending for their children's good quality of life. On observing their expenditure pattern it was seen that more was

spent on essential commodities rather than on amusements such as gifts, holidays and birthdays (106).

3.13 DISABILITY AMONG THE VULNERABLE POPULATIONS

According to Belmont report, vulnerable populations are defined as those who are easily available for research. They bear asymmetrical burden of research (107). Women, children, refugees, disabled, prisoners and patients are some of the vulnerable groups. Such groups willingness to participate in research is influenced by the fact that they have a belief that they will be benefited from the study (108). In the survey of income and program participation conducted in United States, women were observed to have more disability (24.4%) as compared to 19.1% among the opposite sex; the elderly reported more disability (51.8%) (44). In an unpublished study done in South India among elderly, prevalence of disability was found to be 20.6% (109) which is well above the national prevalence of disability which is 1.85% in rural areas according to NSSO 2002 (110).

Women with disability in general face more obstacles in participation than their counterparts, especially in countries like India where gender roles are rigid. They are more disadvantaged than the males since there is inequality in wages, denial of decision making, less access to training and strong cultural beliefs. There is underlying belief among even professionals that women with disability are inert, turn to others for support and are not concerned about getting back to work (111). Women with disabilities are stigmatized and left to be concerned about child bearing, sexuality and body image (112). Disabled women experience twice the discrimination that their male counterparts face. Unlike a male, disabled females feel less accomplished in life because of reduced chances of marriage and higher prevalence of divorce and abuse. They receive heavy scepticism from their families, education is refused or if given only enough which does not promote her social or economic independence (113). The most important reason for disabled

women to be non productive is deficiency in self esteem. Most women report not being considered as a human or as a woman due to their disability. Due to humiliation, difficuly in transport and poor communication skills these women are isolated from mainstream society (114).

Relationship between the poor and disability has been well established. Disability and poverty have a two way relationship. Disability is the cause and effect of poverty. People with disability are at a higher risk of disability and those with disability have higher chances of becoming poor. A survey conducted among elderly poor showed that disability and poverty are related. They observed that every marginal increase in log of per capita expenditure will bring down the likelihood of disability by 0.11 (115).

3.14 NUTRITIONAL STATUS OF DISABLED

Its vital that everyone eats right but the disabled need special mention since their nutrition is negatively influenced by their impairments. The reasons being their impairments dimnishing their oppurtunity of purchasing and cooking varieties of foods, their caregivers deciding to cook easy, narrower range of foods, being old and being institutionalized and consuming monotonous food available there. With all these concerns, weight management and adequate nutrition becomes complex issues for a disabled as compared to a normal person (116).

OBESITY AND DISABILITY

Obesity and disbility go hand in hand. Being obese increases the chances of getting disabling conditions like diabetes, hypertension, cardiovascular diseases, respiratory problems, gall stones, osteoarthritis and cancers. In 1994-1995 National Health Inteview survey in the United States it was found that 24.9% of the disabled adults were obese as compared to 15.1% of non disabled. Significant risk was found among adults with some disabiltiy (Adjusted Odds Ratio (AOR) 2.4; 95% CI 2.3 – 2.5), severe disability (AOR

2.5; 95% CI 2.3 – 2.7) and those lower limb locomotor disability. The Behavioural Risk Factor Surveillance System was conducted in the United States from 1998 to 1999 and the results were analysed by CDC. Of all the people surveyed the disabled were more obese 27.4% (95% CI 25.5-29.3) than those who were non disabled 16.5% (95% CI 15.9-17.1) (117). For those with physical disability, inactivity and muscular atrophy contributes greatly to obesity and for those with mental disability the inadequate diet, medications and poor eating practices are the reasons for obesity (118,119).

3.15 TOOLS FOR ASSESSMENT OF NUTRITIONAL STATUS IN ADULTS

Conventionally weight, BMI, serum protein and dietery changes were used for nutritional assessment of adults but they provide only a snapshot of the nutritional status. They don't predict the complications that could rise out of malnutrition. Their values can be distorted in case of serious comorbidities (120).

Validated tools which can be used to assess the nutritional status of adults are

1. Subjective global assessment scale
2. Patient generated subjective global assessment scale (121)
3. Mini nutritional assessment

SUBJECTIVE GLOBAL ASSESSMENT SCALE (SGA)

It is a simple and easy to administer tool used to assess the nutritional status of adults. As the name suggests it is subjective in nature. It forecasts nutrition related complications. It recognizes malnutrition, it differentiates malnutrition and disease and finds out patients in whom nutritional treatment could change the outcome. It does not depend on physical measurements and diet history both of which patients cannot remember accurately. There are 3 types of overall rates in SGA:-, A - denoting mild malnutrition, B - denoting moderate malnutrition and C - denoting severe malnutrition. It varies from MNA by its nature of assessing hospitalized patients, analysing sudden weight loss, shift in food

consumption, disease related stress and weight loss (120). SGA mainly concentrates on the effect of disease on nutrition. It correlates with anthropometry values, diet history and protein levels (122). In an Indian study done among cancer patients SGA scores were significantly associated with unfavourable outcomes, increased hospital stay and higher mortality. The odds ratio being 2.89 for association between malnutrition and adverse outcomes (95% CI 1.25-6.67) (123). In a study done to measure the level to which the physician's SGA scoring was affected by his training, 202 inpatients were assessed. Multivariate analysis was done and factors which were found to be influenzed by the physician's teachings were loss of subcutaneous tissue muscle wasting and loss of weight. A good degree of interobserver agreement was found (kappa = 0.78, 95% CI 0.624 to 0.944, $p < 0.001$). It was concluded that SGA can be used by clinicians of different classes such as nurses and physicians (124). Its use has been validated among critically ill, dialysis and surgical patients (125–127).

MINI NUTRITIONAL ASSESSMENT (MNA)

It is a non invasive, simple, inexpensive, hands on tool designed especially for the nutritional assessment of the elderly. It was developed by the Nestle nutrition institute. It helps in identifying patients who will advantage from nutritional treatment. It can be used in hospitals or homes by physicians, nurses, other health professionals and care givers. The maximum score in MNA is 30, 16 points from a screening questionnaire and 14 from the assessment component. It is a sensitive and specific tool to assess people at risk of malnutrition. It can be completed within 15 minutes (128,129). Significant correlations were observed between different MNA questions. Body Mass Index (BMI) and calf circumference (CC) ($p = 0.0001$) and correlation coefficient $r = 0.60$. BMI and Mid Arm Circumference (MAC) had a correlation coefficient of 0.54 and correlation coefficient for MAC and CC was 0.52. Reduction in food intake and self view of nutritional status had

r =0.34 (130). The MNA is reliable tool as represented by kappa values of 0.51 for hospitalised geriatric patients and 0.78 for the institutionalized elderly (131). Sensitivity of the scale has been proven to be 96%, specificity 98% and prognostic value for malnutiriton 97%. Two forms have been developed - full and short. The full form has 18 items and includes anthropometry, general assessment, diet related questions and personal assessment on health and nutritional status. MNA short form is a two stepped tool. It has similar validity as the full form (128). The results of the assessment can vary for different populations. Studies done among elderly have criticised its weakness in identifying body composition of elderly. In one study conducted in Wright state University, 23% of the studied population were identified as at risk for malnutrition. The same population had body composition comparable with the group that were identified as normal (132). In a study done among institutionalized elderly, MNA scale was observed to be able to identify individuals with malnutrition among adults with intellectual disability. Participants with cerebral palsy had higher prevalence of malnutrition (133). In one study done among 240 elderly, relationship between functionality and nutritional status was explored and among the activities of daily living partial or complete eating dependence was found in more than 50% of the elderly who were malnourished against 13.4% who were at risk (134). In a study done among 160 patients with parkinsons disease, mobility, Activities of Daily Living(ADL), emotional wellbeing and social support were negatively correlated with MNA total score; all p values were <0.05. Mobility had largest negative correlation (135). In one study done among 353 elderly patients in Brazil, Performance Oriented Mobility Assessment (POMA) and MNA was done. POMA scores were significantly associated with MNA scores and loss of function was observed to be worsened in the presence of malnutrition (136).

3.16 BODY MASS INDEX

The mini nutritional assessement includes calculation of Body Mass Index for the patients. Body mass index was discovered by Adolphe Quetelet as a relative body weight index. He concluded in his studies on human growth that ' weight increases as the square of height' . It was coined as quetelet index (137).

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$$\text{Body Mass Index} = \frac{\text{Weight In Kilograms}}{(\text{Height In Meter})^2}$$

Table 3.4 The International classification of adult underweight, overweight and obesity according to BMI

Classification	BMI Cut offs
Underweight	18.50
Severe thinness	16.00
Moderate thinness	16.00 – 16.99
Mild thinness	17.00 – 18.49
Normal	18.50 – 24.99
Overweight	≥ 25.00
Pre- obese	25.00 – 29.99
Obese	≥ 30.00
Obese class I	30.00 – 34.99
Obese class II	35.00 – 39.99
Obese class III	≥ 40.00

Source: Adapted from WHO, 1995, WHO, 2000 and WHO 2004. Global database on Body Mass Index. Available from http://apps.who.int/bmi/index.jsp?introPageintro html.

WEIGHT MEASUREMENT IN BEDRIDDEN AND CHAIR BOUND PATIENTS

In community dwelling patients, measurement of weight and height using conventional methods becomes difficult. Deformities due to arthritis, congenital conditions, kyphosis and scoliosis makes it all the more complicated. In a study done among 368 people,

significant positive correlation was observed between weight and height, abdominal circumference, arm circumference, calf circumfernece and subscapular skinfold thickness. Weight predicting equation was achieved by multiple linear regression. With only a measuring tape, weight of a bedridden patient can be calculated (138).

Weight in Kilogram = 0.5759 x (arm circumference in cm) + 0.5263 x (abdominal circumference in cm) + 1.2452 x (calf circumference in cm) – 4.8689 x (male = 1/ female =2) – 32.9241

HEIGHT MEASUREMENT IN BEDRIDDEN AND CHAIR BOUND PATIENTS

In a study done among 100 young and 63 elderly people significant correlations between height and total arm length and forearm length were found (139). In another study among 65 and above elderly population, high correlation coefficients were obtained for demi arm span (r = 0.85) (140). In a study done among 17-70 year olds, knee height had a good prediction of height (men r^2 = 79%, women r^2 = 73%) (141). 553 subjects from different ethnic groups were studied to find relation ship between arm-span and height. High correlation coefficient (r = 0.73 - 0.89) was observed between arm-span and height for all ethnic groups (142).

Height measurement in cms from demi arm span for females =
(1.35 x demi arm span) + 60.1
For males = (1.40 x demi arm span) + 57.8
Height measurement in cms from knee height for females =
84.88 – (0.24 x age in years) + (1.83 x knee height in cms)
For males = 64.19 – (0.04 x age in years) + (2.02 x knee height in cms)

MEASUREMENT OF MID UPPER ARM CIRCUMFERENCE

Mark a point perpendicular to the long axis of the upper arm and measure with a tape around the arm. Tape should not be pulled too tight (143).

MEASUREMENT OF CALF CIRCUMFERENCE

1. Expose the calf
2. Let the patient sit comfortably
3. Measure the circumference of the widest part of the calf with measuring tape (144).

MEASUREMENT OF KNEE HEIGHT

1. Make the patient sit comfortably with both legs hanging freely
2. Measure from 4 cm above the front of knee to the lateral malleolus using the lateral malleolus (145).

MEASUREMENT OF DEMI ARM SPAN

1. Ideally measured in standing position
2. Elevate right arm and measure from midpoint of sternal notch to a point between middle and ring finger (145).

MEASUREMENT OF ABDOMINAL CIRCUMFERENCE

In anthropometry the measurement of abdominal circumference is done in the following manner. First, palpate the right iliac crest. Then, draw an imaginary horizontal line at top point of right iliac crest, pointing towards mid axillary line. Place the measuring tape around the abdomen at this level. Measurement is done at minimal respiration (143).

In bedridden and chair bound community dwelling patients it is extremely difficult if not impossible to measure height and weight by routine measures.

3.17 CAREGIVING IN DISABILITY

Caregiving forms the core of family dynamics. Each one in the family cares for another in a unique way. In the United States, 80% of the caregivers are family members for the severely disabled (146). In the Indian country approximately 90% of care is provided by family caregivers (147). Family care givers are the strength of chronic disease care. They

face crisis in emotional, social, medical, economical and spiritual aspects of their life (148). Caregiving in the United States Survey 2009 showed that 28.5% of the population take the role of care giving in their lives, the majority of them being females - 66%. Thirty six percent of all the caregivers are people who take care of their parents and 3 in 10 of caregivers expressed stress (149). Fifty percent of caregivers feel that their health is affected negatively by caregiving (150). A study done in Casa among family members of intellectually disabled children showed that family situations become problematic when a child has psychiatric problems. In this study the mothers of intellectually disabled children identified poor endevour, inadequate support from partners and level of difficulty as factors causing stress (151). Caring opportunity may occur at any point of life and when it happens, it affects the carer's social, economic and physical aspects of life. Some concerns which agonise carer's lives are urinary and defecation problems in the care recepient, loss of sexual relationship, financial constraints, inadequate sleep and risk of suicide by the recepient. Carers often feel neglected, isolated, depressed and upset with the society. They cope better if the patient is their loved one (10).

A study done in the United Kingdom among caregivers of stroke patients showed that patients and caregiver's anxiety are determinants of caregiver burden. Training the caregiver was found to be effective on caregiver burden which was independent of other factors. The level of disability, age, gender and societal support were not found to be associated with caregiver burden (152). In Canada 54% of the caregivers are females (153). Female caregivers report more depression and burden. They also feel that their wellbeing and health is reduced (154).

In a study done among caregivers of stroke patients in Netherlands, younger caregivers, severe stroke, psychiatric effects of stroke and poor social support were found to be at higher risk for strain. Poor mental health was present among caregivers who were female,

being unhealthy physically and among those who took care of patients with psychiatric complications of stroke (11).

3.18 PATIENT REPORTED OUTCOME MEASURES (PROS)

The aim of ideal health care should be to provide patient centered successful treatment (155). Incorporating the patients's viewpoint on treatment and symptoms is vital for any quality care. In the 1980s PROs were introduced as patient's viewpoints on treatment outcomes. Patient reported outcome measures are outcome measures which are from the patient's perspective. They give a better understanding of how patients perceive the quality of health care, symptoms, effect of treatment on their everyday lives and how the disease impacts their quality of life. These measures are being increasingly used in trials, clinical care and quality assessments (156).

The different types of instruments available are, disease specific, generic, utility specific, population specific, individualized, summary items and dimension specific (157,158).

Patient reported oucome measures which measure the functional impairment and disabilities are of keen interest to the physicians. Health related quality of life scales measures symptoms and reduction in activity. Quality of life scales are of primary interest to patients (159).

DISEASE SPECIFIC MEASURES

Features of health and its various domains, pertaining to a particular disease are measured using this measure. It is used when attributes related to disease or a health condition need to be measured. It has been increasingly used in trials as outcome measures. It should contain both disease specific outcomes and severity markers. It is recommended that a generic questionnaire should be administrated along with disease specific measures to obtain a wholesome measure of outcome. Disease specific measures have been criticised

for being restrictive in focus, neglecting important outcomes such as social support, adjustment, etc (160).

GENERIC MEASURES

It can be used in any population with any disease. Multiple domains of health can be studied. In many instances of measurement of health interventions generic measures have been used.

Most of them are constructed around the definition of health put forward by the WHO. There is a general criticism that generic measures construe the domains of health in a narrow manner. Most of them focus mainly on physical functioning and health rather than coping and adaptability (161). Commonly used Generic measures are:

1. Ferrens and powers Quality of Life Index
2. WHO QOL-BREF
3. Euro QOL instrument (EQ5D)
4. Short Form health survey (SF36)

FERRENS AND POWERS QUALITY OF LIFE INDEX

In 1985, Quality Of Life Index (QLI) was created by Ferrens and Powers. Their definition of quality of life was one that evolves from the satisfaction of life. The tool has two parts. The first measures satisfaction with different parts of life and the second part measures the value of each aspect mentioned in first. It measures overall quality of life, health, mental, social and family aspects of quality of life (162). Cronbach's alphas for Ferrens and Powers QLI ranges from 0.73 to .99 across 48 studies. Cronbach’s alpha was 0.70 to .94 for the health domain, and 0.78 to 0.96 for the mental domain. For the social domain, alphas from 23 studies were from 0.71 to 0.92. For the family domain, 19 studies reported alpha values ranging from 0.63 to 0.92. Adequate correlations between QLI and life

satisfaction has been studied as a measure of convergent validity. Ferrens and Powers quality of life index has generic and disease specific versions (163).

THE 36 ITEM SHORT FORM SURVEY (SF-36)

This questionnaire was developed by the RAND corporation in their Medical Outcome Study. It is a versatile tool consisting of 36 questions. It has 8 scales on physical, psychological health measures and a choice based utility index. The final score 0 means complete disability and 100 means no disability. It is a generic measure and can be used on general population as well as on a specific diseased population. It is also used to measure treatment outcomes. Participants are requested to answer the questions with relevance to the past 1 month. Scoring is in a weighted Likert scale for each item. The concepts covered in the questionnaire are vitality, physical functioning, pain, view on health, physical role functioning, emotional, social and mental. The reliability of the questionnaire has been estimated by internal consistency and test-retest methods. The reliability values in almost all studies have crossed the 0.70 standard and most of them have values above 0.80 (164). Construct validity was demonstrated by clear differences across all eight SF-36 scales for patients with identified health problems. Physical functioning scale of the SF-36 was significantly associated with all these grouped activities and is thus a sensitive measure of mild functional losses relevant to independent living. Internal consistency reliability values are greater than 0.70 and reliability values for physical component generally range from 0.87 to 0.90. Reduced floor and ceiling effects have been observed due to five options in answers. Item scale correlations are greater than 0.40 and more or less equal within a scale (165). In a study done among community dwelling adults with Parkinsons disease, SF-36 Inter Class Coefficient test for test retest reliability were all above 0.80 except for social scale (166). Another study done in Australia among 90 stroke survivors showed that SF-36 was simple and rapid to

administer with adequate internal consistency (Cronbach's alpha>0.7). Scores for self care and mental health were significantly varied from those devoid of disabilities. SF- 36 unlike other scales avoids ceiling effect and measures all concepts of functionality except social functioning (167).

EUROQOL (EQ-5D)

The effect of disease and treatment on the quality of life is measured using Quality adjusted life years (QALYs). Utility scores are used to represent a person's choice for a particular health level. Utility is a measure used in health economics to summarize quality of life in cost- utility analysis, which is a very common economic evaluation. It ranges from zero to one. Zero is equivalent to death and one is equivalent to perfect health. The scores enable a description of 245 different types of health states (168). EQ-5D consists of two parts - a descriptive system and a visual analogue scale with worst and best visualized health in top and bottom. The scores range from -0.594 to 1. The EQ-5D was first developed for adults but now a new children's version for 8-18 year olds (EQ-5D-Y) has been developed. EQ-5D covers 5 dimensions namely movement, self care, routine activities, pain and anxiety. Each of the above dimensions is approached through three levels - no, minimal and extreme problem. EQ-5D is one of the most frequently used questionnaires to assess health-related quality of life. It covers holistic aspects of health as well as physical, mental and social functions (169).

QUALITY OF LIFE

The concept of Quality of life has been around since 1940 and it continues to interest health care workers. It started when two researchers in 1940 coined the term "performance status" of cancer patients. Another scale created by Zubrod et al in 1950 was approved by WHO in 1979 mainly for use in chemotherapy. Later in 1970 it was

construed as quality of life. Authors have considered quality of life as individual and personal, concerned with value rather than medical or knowledge approach (170). Presently it is a term which is widely used by physicians, sociologists, economists, statisticians, anthropologists, philosophers and the common man.What defines Quality of life is a broad question.

More and more robust studies on quality of life are being published. It is used to describe a myriad of concepts such as well being, functioning, social adjustments, satisfaction and happiness. Since there can never be one standard definition of quality of life, it has been limited now to health related quality of life for the use of clinicians (171).

In Britain, in-depth interviews conducted among 999 elderly identified certain themes for quality of life and they are decent social bonds, available help, dwelling in house and not institutionalised, feeling secure, good transport facilities, involving in relaxing activities, position in the society and healthy life (172).

QUALITY OF LIFE OF MENTALLY DISABLED

In an in-depth interview conducted among 12 mentally handicapped individuals it was identified that they were profoundly displeased with their public life, independence and chance to develop skills at their homes (173). Mentally disabled individuals are generally satisfied with services provided but they express that services tend to infuse a sense of dependency on them. Contrary to traditional beliefs the intellectually disabled are aware of the stigma and hatred the society has meted out to them. Despite these fragments of abounding information of versions of quality of life of the mentally disabled, it is very complicated and time consuming to develop a quality of life questionnaire for the mentally disabled (174).

As compared to the physically disabled, the mentally disabled experience twice the amount of disability. Not only do they have to suffer from the disease but also by the

stigma, hatred and false belief expressed by the others. The general population do not recognize that it is the illness which is causing the person to behave in a particular way. This results in a mentally ill person being deprived of prospects that characterize good quality of life such as employment, health and good relations. The general public considers people with mental illness to be responsible for their own illness (175).

Contextual issues around quality of life of intellectually disabled include downsizing economics, assignment of resources for them and creation of disability movement. The notion of quality of life among intellectually disabled is only emerging. There is significant arguments regarding its conceptualization and measurement (176).

WHO QUALITY OF LIFE QUESTIONNAIRE

WHO describes quality of life as a person's insight of their lives, in view of their traditions in association with their objectives, hopes, standards and worries. It is an extensive idea multidimensional and it is influenzed by a person's health, mental status, freedom level, social interactions and faith. WHOQOL instruments focus on the individual's viewpoint of the disease. WHOQOL-100 was expanded in 15 field centres around the world. Features of quality of life are based on comments made by patients, healthy people and health professionals from mixture of cultural settings. It has good validity and reliability. It generates facets of quality of life and scores for domains, overall quality of life and health.

The WHOQOL-BREF can be self administered, but if the respondents have difficulty in understanding, it can be interviewer administered or assisted. Initially a raw scoring of each domain is done which will be in the 4-20 range. The transformed score can then be converted into domain scores ranging from 0-100 (177). WHOQOL-BREF instrument helps the physician select best options in care of a patient, determine increase or decrease

of quality of life after treatment, Evaluate health care services, improve the patient doctor relationship, in research and policy and programming (178).

PSYCHOMETRIC PROPERTIES OF WHO QOL-BREF

Psychometric properties of WHO QOL-BREF has been well established. In a study done among 1200 elderly people living in the community, all the domain scores of WHO QOL-BREF showed excellent discriminant and construct validity, good internal consistency and inter and intra-observer test-retest reliabilities (179). In another study done among 147 spinal cord injury patients, excellent intra- class correlation coefficient of 0.84 was observed for overall quality of life. Excellent inter and intra-class correlation coefficient was observed for physical and psychological well being also among this population (180).

In a study done among 1210 adults in Iran, adjusted mean scores for all domains were significantly different for the healthy and the ill individuals. Most questions showed high correlation with their domain of origins. Correlation between WHOQOL-BREF and SF-36 was observed and it was more than 0.45 for all domains (181).

A study done in Iran showed that healthy population enjoyed a better quality of life as compared to people suffering from musculo-skeletal conditions, cardiac diseases, endocrine problems and other chronic diseases. This observation reflects the ability of WHOQOL-BREF to distinguish healthy and sick individuals (182).

Table 3.5 Domains in WHOQOL-BREF and their corresponding facets

PHYSICAL HEALTH	**1.** Activities of daily living **2.** Reliance on medical treatment or aids **3.** Energy / tiredness **4.** Movement **5.** Pain and discomfort **6.** Sleep and rest **7.** Work and capacity
PSYCHOLOGICAL	**1.** Bodily image and appearance **2.** Negative feelings **3.** Positive feelings **4.** Self-esteem **5.** Spirituality / Religion / Personal belief **6.** Thinking / learning / memory / concentration
SOCIAL RELATIONSHIP	**1.** Personal relationships **2.** Social support and sexual activity
ENVIRONMENT	**1.** Financial resources **2.** Freedom, physical safety security **3.** Health and social care: accessibility and quality **4.** Home environment **5.** Opportunities for acquiring new information and skills **6.** Participation and opportunities for recreating leisure activities and physical environment **7.** Transport

Source: WHO QOL-BREF. Introduction, Administration, Scoring and Generic version of the assessment. Field trial version. December 1996. Programme on mental health. WHO.

QUALITY OF LIFE OF PEOPLE WITH DISABILITIES

General understanding of good quality of life is personal well being, good health and satisfaction with life (183). There is a general consensus that people with disabilities cannot be considered to be enjoying good health, since they have an impairment. Poor participation in society, stigma and discrimination can contribute to poor life satisfaction

(184). How ever quality of life is a complex phenomenon and a person with disability's viewpoint of health satisfaction with life and well being contradicts their observed health status and disability (185). Disability and quality of life are similar concepts since both measure patient's experiences. However both do not illustrate the same phenonmenon and should be understood as different measurements (186).

Advancing disease conditions result in poorer quality of life as compared to stable disease state. Getting accustomed to a disease plays a major role in determination of quality of life of a person with disability. Not only does the severity of the disability affect one's quality of life but also the occupational status and social participation. It is observed that younger people adapt without much difficulty in comparison with the middle aged. That phenomenon is attributed to the fact that the middle aged have spent considerable amount of life years in getting trained or educated for a particular employment and a disability shatters all the efforts (187). The relationship between employment conditions and quality of life is well established. A decent salary and independence at work seem to predict good quality of life. In secure job, jobs that are not interesting, stressful and intense work indicate low job satisfaction and inturn affect the quality of life. All these aspects of employment affect the quality of life of person with disability as well (188).

A study done among 167 people with disability in Bangladesh, showed that 71.9% reported difficulty in school attendance due to disability, 79.7% indicated that their disability affected their occupation, 27.5% of those who were employed reported earning less as compared to those without disability, 26% of the disabled were compelled to change their occupation due to disability, 47.5% of disabled revealed that they were unable to marry due to disability, 24.3% of disabled had emotional problem such as anguish and guilt arising due to disability, 18.4% expressed not having a job as the reason for the misery and 32.6% were considered as a burden to the society (189).

In a study done among 605 lower limb amputees employment status and use of prosthesis was found to affect the quality of life (190). In a study conducted among 270 traumatic spinal cord injury patients, it was found that they had significantly lower quality of life than the country norms for all domains of Quality of life in WHOQOL- BREF. The difference was mainly observed in physical domain and social domain. Quality of life was significantly associated with disability. The most significant predictor of QOL was conditions secondary to the injury like pain and infections followed by social involvement (191). A study was conducted among 86 stroke patients. Quality of life was assessed by four domains - physical, social, family and mental. 33% of the participants were found to be depressed, but the mean overall quality of life score was high and measured up to quality of life of people without disability. Depression, social sustainment and functionality were predictors of quality of life (192). In a study which interviewed 153 disabled patients, 54.3% of the severely disabled had excellent quality of life despite constrained income and benefits. This is explained by a phenomenon called "disability paradox". The patients despite having serious disabilities, impairments, poor participation in the society and being objects of stigma and discrimination express good quality of life. This contrasts with the perspective of physician, therapists and general public that disabled experience poor quality of life. Those with disabilities were able to continue their familial roles and had control over body, mind and lives. Many disabled felt satisfied about themselves despite others despising them. Some of them even provided moral support to others which upgraded their levels of responsibility and participation. Many turned to religion and spirituality which helped them experience abundant life despite burdens. Disability brought out hidden strengths and resilience in people and helped them establish stable values about life. Some expressed that it brought maturity and straightened them out. One can safely conclude that all these responses were not

expressions of deniel but ones with optimism, recognition of one's disability status, knowledge of responsibilities, continuing to play familial and social roles and searching for a meaning in life through spirituality or other means.

However upto 50% of disabled have also reported poor quality of life. Factors contributing to poor quality of life include pain, fatigue, aimless life, feeling of no contribution to society or family and no faith in God (4). In a study conducted among 147 traumatic brain injury patients lesser scores for psychological domain was found to be significantly associated with previous low scores before injury, alcohol intake during injury, more severe disability, poor social support and symptoms of depression. Not having a spouse was found to be associated with lesser scores in social domain (180).

In a study conducted in Europe among 386 Spinal Cord Injury (SCI) patients who were employed, work stress was assessed by Effort-Reward Imbalance model (ERI). ERI was observed to be associated with all domains of quality of life. Education was inconsistently associated with quality of life. Among those who had financial problems, 33% of them rated their quality of life as poor. Imbalance at wok resulted in poor quality of life and lesser health satisfaction (193).

Disabled elderly population identifies family, friends, neighbours support, social involvement and faith on the physician as factors influencing quality of life (194). A study done among physically disabled adolesccents in Kerala revealed that 72% of them had average quality of life, 12% had poor quality of life particularly in environment and psychological domains and 92% of them were found to be dissatisfied with the transport section of environment (195). In another study done among adolescents in California, significant difference in Quality of life scores was observed between disabled and non disabled adolescents (196).

3.18 CAREGIVING AND QUALITY OF LIFE

In today's world families are doing the work of institutions in taking care of a disabled person. The primary caregiver is defined by one who forms the patient's informal support system, takes care and responsibility of the patient and spends most of his or her time with the patient with out any economical rewards (197). In a sytematic review of caregiver quality of life among caregivers of schizophrenia, it was found that health of the caregivers was worsened due to caregiving. Problems in caregivers life includes stress, anxiety and depression. Employment status of the caregivers was challenged due to the amount of time spent with the patient. Most of them had to quit jobs or change timings of their work which ultimately had an impact on the economic status of their families. Stress was multiplied due to their multiple job responsibilities like household activities, employment and caring for the patient. In developing countries like India and Chile much of the problem was experienced due to inadequate health services. Main factors associated with poor quality of life were the number of roles played, poor social and employment support, worsening illness and disturbed family life (198).

Caregivers of elderly people with physical disabilities had various domains of quality of life affected such as amount of caregiving burden, health and economic status of the individual (199). A study done among 597 caregivers of children with intellectual disabilities, the mean score of each domain in WHO QOL-BREF were physical 13.71 ± 2.35, mental 12.21 ± 2.55, social 12.99 ± 2.43 and environment 12.32 ± 2.3. All scores were lower as compared to general population. Family income, self perceived health status and tension, poor support from others in family were identified as significantly correlating with all domains of QOL (200). A study done among caregivers of patients with parkinson's disease showed that being a female caregiver, carers with long standing illness and elderly caregivers were at risk for poor quality of life. Cognitive impairment

and difficulty in mobility among the patients and duration of caregiving were found to be predictors for poor quality of life among caregivers (201).

3.19 QUALITATIVE RESEARCH IN DISABILITY STUDIES

Qualitative studies often close the gap between research and implementation of results of the research. They are different from quantitative studies since quantitative studies transform data into numbers and utilizes statistics and mathematical models for interpretation of result and qualitative studies on the other hand handle lesser amount of numbers and statistics. In quantitative studies the researcher and the research instruments are two separate units but in a qualitative study the researcher himself is the research instrument (202). There are criticsms on this since the researcher's personal perceptions can control the evidence and hence this type of research is now demoted to marginal levels of science especially when trying to establish causal relationships (203). However when it comes to study of culture, attitudes, knowledge beliefs and perceptions of people, qualitative research is a superior tool. Qualitative method of research is valuable when the study popultion is vulnerable as in the case of disabled. Moreover available studies on disability are more quantitative in nature focussing on physical impairments, heavily relying on medical model. Qualitative studies draw a parallel line with social model. Disability as such is complex, multidimensional and people's insight into it are equally intricate. Such situations call for data from anthropology, sociology and psychology for a robust research. Qualitative research can effectively compliment the results of quantitative studies done on disability by looking into the cultural pracrices, beliefs and perceptions in relation to disability (204).

Qualitative research has five approaches namely, Ethnography, Grounded theory, Case study, Phenomenological research and narrative research.

ETHNOGRAPHY

In the early 1900s Bronislaw Malinowski and Alfred Radcliffe Brown observe communities over a period of time and studied their beliefs and activities of social importance. It formed one of the first of its kind ethnographic studies. Characteristic features of ethnographic studies include

1. Whole some view of society's perspectives, notions through thorough observation and interview
2. Mostly involving collection of formless data
3. Studying less number of cases in larger details
4. Analysis involves spoken descriptions and meanings of description (33).

GROUNDED THEORY

Proposing a theory progresses over a research. In qualititative studies, theories are grounded on the views and opinions of the participants of the study. Sociologists consider grounded theory to be more accomplished than theories based on reason and judgement (205).

CASE STUDY

This method of qualitative research is used in the following situations

1. Aim of the study is to find out how and why.
2. Researcher has no influence on the behaviour of the group that he is studying
3. There are grey areas between the observable facts and actual situation

There are two types of case studies

1. Single
2. Multiple

Single case study gives the entire picture of a particular situation as in different opinions of different people on seeing a disabled person.

Multiple case studies examines different opinion of different people on different types of disability. It is cumbersome and costly as compared to single case study (206).

PHENOMENOLOGICAL RESEARCH

Phenomenology is the study of knowledge from an individual's viewpoint. Epistemiologically this method is highly subjective. Through qualitative methods such as interviews, discussions and observations it attempts to collect data on perceptions, knowledge andexperience and the results can be translated into meaningful data which can explain the motivations and reasons behind why certain individuals or societies act in certain ways (207).

NARRATIVE RESEARCH

It involves collection of narrations written, verbal or observations, in quest for understanding of the intricate subjects of life. They can be taperecorded, written down, transcribed and analysed. It may simulate interviews but the interviewer should maintain transparency and strike a balance between the influential power of interviewer and interviewee (208).

FOCUS GROUP DISCUSSION

It is a part of participatory action research. This type of research is compared to a concept called emancipatory research where the participants have complete power over the research (209).

Focus group discussion is a quick evaluation and semi structure data collection method in qualitative research. It involves a focused and selective participants who assemble to narrate and converse on topics described by the investigator (210). A focus group is a group of six to ten people directed by the moderator. The numbers should be such that the group is larger enough for meaningful discussion and not so large that few people feel excluded.

The researcher needs to drive the group on the objectives and research questions involved, simplify complex ideas and hypothesis into simple open ended questions. The moderator of the focus group discussion needs to be well versed with the topic, language of the, expressing authentic interest in the people, sensitive to gender disparity, mannered and compassionate (211) **.** The moderator aims to produce the maximum number of thoughts and viewpoints from various people during the discussion within the limited period of time of 45 to 90 minutes. After that time, most discussions do not turn out to be constructive. Focus groups are arranged around a series of well framed questions around 10 in number. The group comprises of a similar group of strangers the homogeneity reduces restrains in expressing opinions. Questions should not be intimidating or embarrassing but open ended for which answers should be why and how (212). Most of the focus group discussions done in literature is to assess needs of the disabled (213). One study done in China attempted to identify the domains of quality of life disabled through focus group discussion. All the five domains (physical, mental, social, economic and environmental) were recognised by comparing themselves with self and others (214).

4. MATERIALS AND METHODS

4.1 STUDY SETTING:

The study was conducted in Kaniyambadi block, a revenue block located in Vellore District, Tamil Nadu, India. It is predominantly a rural area with a population of one lakh twenty thousand. There are a total of 88 villages in this block. Three primary health centres, one governement medical college and the Department Of Community Health, Christian Medical College(CMC) serve to meet the medical needs of this area. Below is the GIS map of Kaniyambadi block.

In addition to the public health cadre of the Tamilnadu Government who work through the primary health centres, the Department Of Community Health, CMC has its own public health unit comprising of part time community health workers (PTCHW) who form an essential link between the community and the public health system. The PTCHW inturn is supervised by Health Aides who cover a population of about 5000. They are 17 in number. Their work consists of gathering vital statistics, immunization status and follow up of patients with chronic diseases. They provide basic antenatal, newborn and child care. They assist the doctors and nurses in the outreach clinics. These health aides are supervised by a Public Health Nurse (PHN) who is incharge of a 25,000 population. She visits the communty thrice a month through outreach clinics. A community health post graduate student is responsible for a population of about fourty thousand and he/she visits the community through outreach clinics conducted once in a month. An occupational therapist and four social workers work in close association with the public health team to serve this area. A community health professor supervises the entire cadre.

The Health Information System(HIS) in the Community Health department, CMC consists of a well organized computer network maintained by a team which includes a

statistician and computer entry personnel. They extract data from the health aides and convert into information. Information regarding vital statistics, immunization, chronic diseases, disability can be obtained from the Health Information System and follow up and care of the patient is made feasible through this network.

4.2 STUDY DESIGN

The first part of the study was a cross sectional observational study among a sample of disabled from this block and among their primary caregivers. The second part of the study included focus group discussions to complement the cross sectional study. The field component of the study was carried out between November 2013 to August 2014.

4.3 STUDY POPULATION

INCLUSION CRITERIA

1. Persons with disabilities aged 18 and above who were permanent residents of the Kaniyambadi Block
2. Primary caregivers of the above mentioned persons with disabilities.

EXCLUSION CRITERIA

1. A person with disability without a primary caregiver

4.4 SAMPLE SIZE

Sample size calculation for a cross sectional study design

$$n = \frac{Z^2 \times P \times (1 - P)}{d^2}$$

n = sample size

Z = For a normal distribution, 95% of the values fall between 2 standard errors of the mean. The corresponding Z value is 1.96. It can be rounded to 2.

P = prevalence of poor quality of life among disabled taken as 13%

d = precision (margin of error) of 4

Anticipating 5-6% non response, The required sample size is 300.

4.5 SAMPLING METHOD

Simple random sampling was followed as the method of sampling. The sampling frame which was the list of total number of persons with disabilities residing in Kaniyambadi block was obtained from the Health Information System(HIS) of Community Health Department. A total of 600 disabled persons were selected using a table of random numbers. Twice the required sample size was initially listed to compensate for any unavailable individuals and for non response

4.6 METHODOLOGY

The study was presented to the Institutional Review Board and Ethics committee of Christian Medical College, Vellore. After their approval, the data collection was initiated. As described earlier 600 disabled persons were listed in order by simple random sampling method. The principal investigator visited the household of each disabled person as in the list and interviewed the person with disabilities and their primary caregiver. If the person with disability was not available, the next person in the list was chosen. The health aide, PTCHW and an occupational therapist, accompanied the investigator in most of the interviews to develop a good rapport and help produce a conducive environment before administrating the questionnaire. Informed consent was obtained from both the person with disability and their primary caregiver. If the participant was person with mental

disability and unable to comprehend the details of the study, informed consent was obtained from the primary caregiver. The study questionnaire was administered by the investigator and was followed by measurement of the relevant anthropometric measures of the disabled individual.

In the second part of the study, two focus group discussions were conducted. The first discussion was among persons with disability and the second, among the primary caregivers. A focus group guide, separately for the person with disability and their caregivers was prepared. The topics covered for the persons with disability were social problems of disablity, barriers and hindrances, involvement in community activities, quality of life of persons with disabilities and factors affecting it, negative feelings associated with disability and impact of disability on the family. Topics covered for the primary caregivers were quality of life and factors affecting it, frequency of negative feelings, health status of caregivers, capability of caregivers to provide care, types of disability and difficulties in caregiving, type of relation and caregiving, and satisfaction in caregiving. The number of participants in the persons with disabilities group was 8 and caregivers group was 9. Among the persons with disabilities group only individuals with locomotor disability were invited due to concerns regarding communication among persons with mental disabilities. Among the primary caregivers, caregivers of individuals with both physical and mental disability participated in the focus group discussion. One of the study team member moderated the discussion in native language as per the guidelines prepared. The principal investigator transcribed in writing and another member recorded the conversation in a voice recorder after informing the participants. The transcribed documents were translated into english and analysis was done.

4.7 TOOLS

1. A questionnaire regarding the demographic, socio-economic, disability, relationship and duration of caregiving and health status of the person with disability.
2. The WHOQOL-BREF to determine the quality of life
3. The Mini Nutritional Assessment scale (MNA)
4. Functional status assessment - International Classification Of Functioning, Disability and Health (ICF) grading
5. WHO Disability Assessment Schedule 2.0 (DAS)

4.71 QUESTIONNAIRE 1:

From this questionnaire age, sex, marital status, educational and occupational status of the person with disability, the socioeconomic status according to Modified Kuppusamy's scale, type, duration and cause of disability and use of aids, comorbid conditions, benefit from social security schemes and caregiver relationship and duration were analysed.

4.72 WHOQOL-BREF:

Tamil version of the WHOQOL-BREF was administered to the persons with physical disabilities and all the primary caregivers. It consists of total of 26 questions. 24 questions are taken from WHO QOL 100 from each one of its facets. The remaining two questions are on individual's perception of his/her quality of life and general health. The responses to the WHOQOL-BREF were in a 5 point likert's scale. The four domains of quality of life were given scores as per instructions in the following table. Mean score of items within every domain were used for domain score. These mean scores were multiplied by 4 to make the score comparable to that of WHO QOL 100.

Table 4.1 Computation of domain scores for the WHO QOL-BREF

Domains	Formula for calculating domain scores	Raw scores	Transformed scores
Domain 1	(6-Q3)+(6-Q4)+Q10+Q15+Q16+Q17+Q18		
Domain 2	Q5+Q6+Q7+Q11+Q19+(6-Q26)		
Domain 3	Q20+Q21+Q22		
Domain 4	Q8+Q9+Q12+Q13+Q14+Q23+Q24+Q25		

4.73 MINI NUTRITIONAL ASSESSMENT SCALE

Body mass index (BMI) was calculated after measuring height and weight. Classification of BMI done as per WHO cut offs for asian ethnic groups. According to the screening scores of MNA participants were classified into malnourished, at risk of malnutrition and normal nutritional status. The malnutrition indicator scores were calculated and based on the scores, participants were classified into malnourished, at risk of malnutrition and normal nutritional status.

Formula for weight calculation among beddridden patients

Weight in Kilogram = 0.5759 x (arm circumference in cm) + 0.5263 x (abdominal circumference in cm) + 1.2452 x (calf circumference in cm) – 4.8689 x (male = 1/ female =2) – 32.9241

Formula for weight calculation in amputees

$$\text{Estimated body weight of an amputee} = \frac{\text{Current body weight}}{(1 - \text{proportion for the missing body part})}$$

Table 4.2 **Percent of body weight contributed by specific body parts**

Missing body part	Percent contributed
Trunk without limbs	50.0
Hand	0.7
Forearm with hand	2.3
Forearm without hand	1.6
Upper arm	2.7
Entire arm	5.0
Foot	1.5
Lower leg without foot	4.4
Lower leg with foot	5.9
Thigh	10.1
Entire leg	16.0

Formula for height measurement: Height measurement in cms from demi arm span for females = (1.35 x demi arm span)+ 60.1 **For males** (1.40 x demi arm span) + 57.8

Height measurement in cms from knee height for females = 84.88 – (0.24 x age in years) + (1.83 x knee height in cms)

For males = 64.19 – (0.04 x age in years) + (2.02 x knee height in cms)

Formula for BMI: Body Mass Index = $\frac{\text{Weight In Kilograms}}{(\text{Height In Meter})^2}$

Scoring for screening and malnutrition indicator was as follows

Table 4.3 Screening scores for Mini Nutritional Assessment (MNA) Scale

Screening score	Outcome
12 to 14 points	Normal nutritional status
8 to 11 points	At risk of malnutrition
0 to 7 points	malnourished

Table 4.4 Scoring of malnutrition indicator score in Mini Nutritional Assessment (MNA) Scale

Malnutrition indicator score	Outcome
24 to 30 points	Normal nutritional status
17 to 23.5 points	At risk of malnutrition
Less than 17 points	malnourished

4.74 FUNCTIONAL STATUS ASSESSMENT

This was done using the International classification of functioning, disability and health (ICF) grading on domains of self care, communication, functional ability and mobility, mental functions, sensory functions and common roles in home and community.

Table 4.5 **International Classification Of Functioning, disability and health (ICF) grading**

QUALIFIER	DESCRIPTION	PERCENTAGE
0	No difficulty (none, absent, negligible)	0 – 4 %
1	Mild difficulty (slight, low)	5 – 24 %
2	Moderate difficuty (medium, fair)	25 – 49 %
3	Severe difficulty (high, extreme)	50 – 95%
4	Complete difficulty (total)	96 – 100 %
9	Not applicable	

4.75 WHO DISABILITY ASSESSMENT SCHEDULE DAS 2.0

Domain specific scores were calculated for the following 6 domains- cognition, mobility, self-care, getting along, life activities and participation. Mean scores for each domain and standard deviation were calculated.

4.8 ANALYSIS OF FOCUS GROUP DISCUSSION

The transcript was first cleaned of non essential words. Disabled group was given the number 1 and every participant in the group was given a code number starting from 1 to 8. Caregivers group was given the number 2 and every participant in the group was given a code number starting from 1 to 9. In 2 separate excel sheets participant identity code number and responses were entered. After all the comments were entered, common themes across the discussion were identified. They were summated into categories and subcategories and short paragraphs describing the findings for each of them and was written down in detail.

4.9 DATA ENTRY AND ANALYSIS

Data entry for the cross sectional study was done in Epidata 3.1 software and analysis done in Statistical Package for Social Sciences (SPSS) version 16.0.

4.91 ANALYSIS PLAN

Univariate analysis was performed by calculating frequencies and percentages for variables such as socio-demographic details, type of disability, cause of disability, malnutrition, relation of primary caregiver duration of caregiving and comorbidities.

Bivariate analysis was done using the Chi-square test and odds ratio to determine any statistically significant association and the strength of the associations between quality of life scores of disabled and primary caregiver with factors such as socio-economic status, type of disability, nutritional status and level of disability.

5. RESULTS

A total of 300 people with disabilities and 300 primary caregivers were enrolled in the study. They belonged to a total of 54 villages spread across the Kaniyambadi block.

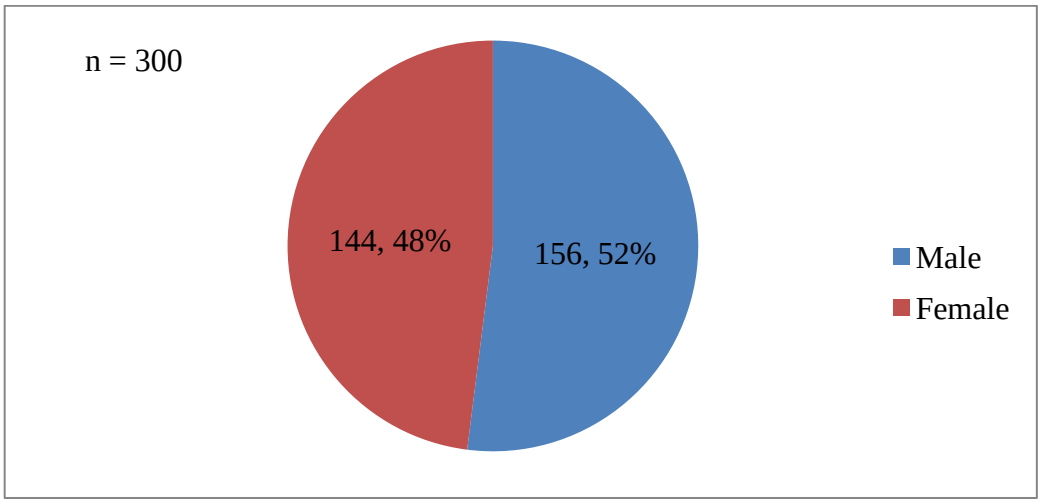
Below is the description of the study population.

Table 5.1 Distribution of people with disabilities by age

Age Category	Frequency	Percentage
18 – 29	64	21.3%
30-39 years	52	17.3%
40-49 years	53	17.7%
50-59 years	46	15.3%
60-69 years	41	13.7%
70-79 years	32	10.7%
80-95 years	12	4.0%
Total	**300**	**100%**

Among the 300 people with disabilities, 21.3% of them belonged to the age group 18-29 years. There were 33.0 % of the 40-59 years age group. The elderly who were 60 years were 85 in number and formed 28.3% of the people with disabilities.

Figure 5.1 Distribution of the people with disabilities by gender



Of the 300 people with disabilities, 52% of the study population were males and 48% were females.

Table 5.2 Distribution of people with disabilities by marital status

Marital status	Frequency	Percentage
Single	134	44.7%
Married	110	36.7%
Widowed	48	16.0%
Seperated/divorced	8	2.7%
Total	**300**	**100%**

Of the 300 people with disabilities 36.7% of them were currently married and 44.7% were single. The seperated and divorced formed 2.7% of the people with disabilties.

Table 5.3 Distribution of the people with disabilities by literacy status

Literacy status	Frequency	Percentage
Illiterate	158	52.7%
Read only	17	5.7%
Read and write	125	41.7%
Total	**300**	**100%**

More than half (52.7%) the people wth disabilities were illiterate and 41.7% could read and write.

Table 5.4 Distribution of the people with disabilities by education

Education	Frequency	Percentage
Nil	134	44.7%
Primary school	36	12.0%
Middle school	55	18.3%
High school	49	16.3%
Higher Secondary	9	3.0%
Post high school Diploma	4	1.3%
Graduate / Post Graduate	12	4.0%
Profession / Honours	1	0.03%
Total	**300**	**100%**

One thirty four (44.7%) of the people with disabilties had no education. Only 18.3% completed middle school.

Table 5.5 Distribution of the people with disabilities by occupation

Occupation	Frequency	Percentage
Unemployed	223	74.3 %
Unskilled	32	10.7 %
Semi-skilled	5	1.7 %
Skilled	17	5.7 %
Clerical / Shop-owner / Farmer	17	5.7 %
Semi-profession	3	1.0%
Profession	3	1.0%
Total	**300**	**100%**

Most (74.3%) of the people with disabilities were unemployed. Among those who were employed, 10.7% of them were involved in unskilled work.

Table 5.6 Distribution of the people with disabilities by total monthly family income (in Rupees)

Total monthly family income (in Rupees)	Frequency	Percentage
≤ 1600	19	6.3%
1601 – 4809	105	35.0%
4810 – 8009	93	31.0%
8010 – 12019	34	11.3%
12020 – 16019	18	6.0%
16020 – 32049	28	9.3%
≥ 32050	3	1.0%
Total	**300**	**100**

The total monthly family income of each household was classified according to modified kuppusamy's socio economic status classification and 35% of the people with disabilities had a total monthly family income of Rupees 1601- 4809.

Table 5.7 Distribution of the people with disabilities by education of the head of the household

Education of the head of the household	Frequency	Percentage
Nil	91	30.3%
Primary school	47	15.7%
Middle school	60	20.0%
High school	75	25.0%
Higher secondary	15	5.0%
Graduate / Post Graduate	5	1.7%
Profession	7	2.3%
Total	**300**	**100%**

Most (30.3%) of the households of the people with disabilities had an illiterate head of the household. Of the head of the households who have been educated, 15.7% of them had completed primary school, 20% of them had completed middle school and 25% of them had completed high school.

Table 5.8 Distribution of the people with disabilities by occupation of the head of the household

Occupation of the head of the household	Frequency	Percentage
Unemployed	93	31.0%
Unskilled worker	79	26.3%
Semi-skilled worker	11	3.7%
Skilled worker	52	17.3%
Clerical, Shop-owner, Farmer	54	18.0%
Semi- profession	10	3.3%
Profession	1	0.3%
Total	**300**	**100%**

Among the head of the household of the people with disabilities 31% of them were unemployed, 26.3% of them were involved in unskilled work.

Table 5.9 Distribution of the study population by socioeconomic status

Socio economic status	Frequency	Percentage
Lower	36	12.0%
Upper-lower	175	58.3%
Lower- middle	77	25.7%
Upper-middle	12	4.0%
Total	**300**	**100%**

None of the study population belonged to high socio economic status as per the modified kuppusamy scale. Most of them (58.3%) belonged to upper- lower socioeconomic status.

Table 5.10 Distribution of the study population by type of house

Type of house	Frequency	Percentage
Hut	25	8.3%
Kutcha	6	2.0%
Mixed	24	8.0%
Government house	17	2.7%
Pucca	220	73.3%
Mansion	8	2.7%
Total	**300**	**100%**

Out of the study population 73.3.% of them lived in pucca houses. Only 8.3% and 2.0% of them lived in huts and kutcha houses respectively.

Table 5.11 Distribution of the study population by type of family

Type of family	Frequency	Percentage
Nuclear	187	62.3%
Joint	86	28.7%
Extended	27	9.0%
Total	**300**	**100%**

Most (62.3%) of the study population belonged to nuclear families.

Table 5.12 Distribution of the study population by religion

Religion	Frequency	Percentage
Hindu	279	93.0%
Christian	18	6.0%
Muslim	3	1.0%
Total	**300**	**100**

Of the study population 93% belonged to hindu religion.

Table 5.13 Distribution of impairments among the people with disabilities

Type of impairment	Frequency	Percentage
Motor	183	61.00 %
Hearing/ Speech	70	23.33 %
Intellectual	60	20.00 %
Psychiatric	46	15.33 %
Visual	38	12.67 %
Seizures	26	8.67 %
Dyspnoea	10	3.33 %
Others	3	1.00 %
Number of persons with disabilities	**300**	**100%**

Of the 300 people with disabilities, 183 (60%) had motor impairment and 70 (23.3%) had hearing/speech impairment.

Table 5.14 Distribution of people with disabilities by number of impairments

Number of impairments	Frequency	Percentage
One	182	60.7%
Two	72	24.0%
Three	30	10.0%
Four	12	4.0%
Five	3	1.0%
Seven	1	0.3%
Total	**300**	**100%**

Of the 300 people with disabilities 39.3% of them had more than one impairment.

Table 5.15 Distribution of people with disabilities by type of disability

Type of disability	Frequency	Percentage
Physical	203	67.7%
Mental	39	13.0%
Physical and Mental	58	19.3%
Total	**300**	**100%**

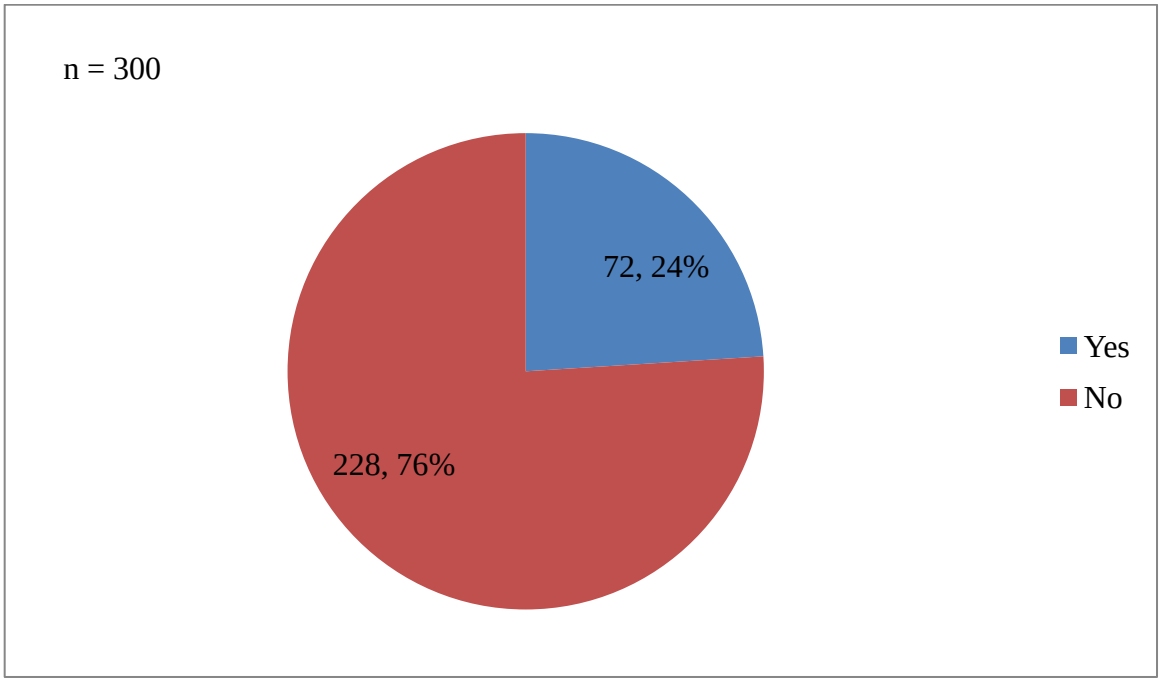
The most common type of disability was physical (67.7%). Mental disability was present among 32.3% of the people with disabilities.

Table 5.16 Distribution of the cause of disability among the people with disabilities

Cause of disability	Frequency	Percentage
Chronic diseases	106	35.3%
Congenital	87	29.0%
Infectious diseases	58	19.3%
Trauma	47	15.7%
Others	2	0.7%
Total	**300**	**100%**

Chronic diseases formed the leading cause (35.3%) of disability among the people with disabilities. Congenital conditions caused 29% of the disabilities. Most common infectious cause of disability was polio 35 (60.3%) followed by hansens disease 5 (8.6%).

Figure 5.2 Distribution of people with disabilities by presence of co-morbidity



Of the 300 people with disabilities, 24% of them had atleast one co-morbidity.

Table 5.17 Distribution of people with disabilities by type of co-morbidity

Types of co-morbidities	Frequency	Percentage
Hypertension	35	33.01%
Diabetes	25	23.58%
Stroke	24	22.64%
others	13	12.26%
Hypothyroidism	7	6.60%
Coronary artery disease	2	1.88%
Total	**106**	**100%**

The most common co-morbid condition present among the people with disabilities was hypertension (33.01%) followed by diabetes (23.58%).

Table 5.18 Distribution of people with physical disabilities by use of aids

Use of Aids	Frequency	Percentage
Yes	65	24.9%%
No	196	75.1%
Total	**261**	**100%**

Among all the people with disabilities, 24.9% of them used some form of aid.

Table 5.19 Distribution of different types of aids used by the people with physical disabilities

Type of Aids	Frequency	Percentage
Wheel Chair	25	38.5%
Walking stick	18	27.7%
Crutches	13	20.0%
Hearing Aid	4	6.2%
Others	5	7.7%
Total	**65**	**100%**

Wheel chairs were the most commonly (38.5%) used aids among the 261 people with physical disabilties.

Table 5.20 Distribution of the people with disabilties by receipt of disability pension

Disability pension	Frequency	Percentage
Yes	159	53%
No	141	47%
Total	**300**	**100%**

More than half (53%) of the people with disabilities benefited from disability pension which is a social security scheme for people with disabilities, offered by the government.

Table 5.21 Alcohol or tobacco use among males with disabilities

Substance use	Frequency	Percentage
Yes	31	19.9%
No	125	80.1%
Total	**156**	**100%**

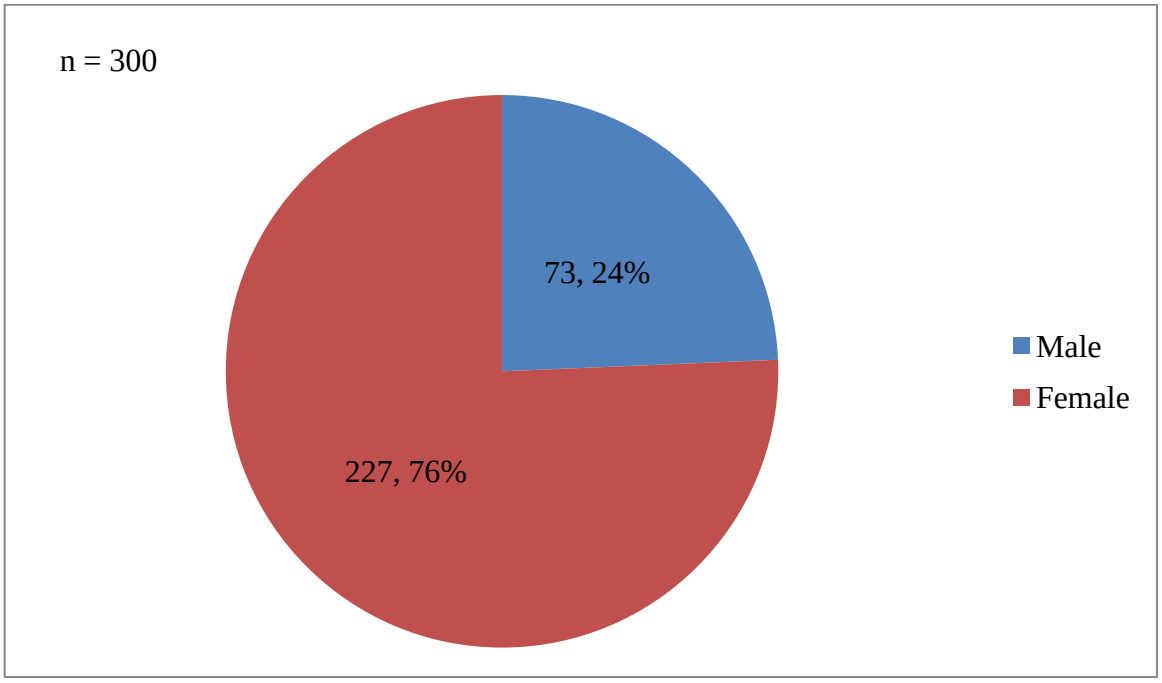
Use of alcohol or tobacco was present among 19.9% of the males with disabilities. None of the female population used alcohol or tobacco.

Table 5.22 Distribution of Body Mass Index (BMI) of persons with disability as per the WHO classification

BMI Category	Frequency	Percentage
Severe thinness (<16.00)	30	10.0%
Moderate thinness (16.00-16.99)	14	4.7%
Mild thinness (17.0 – 18.49)	30	10%
Normal (18.5 – 24.99)	155	51.7%
Pre obese (25 – 29)	51	17.0%
Obese class I (30 – 34.99)	18	6.0%
Obese class II (35 -39.99)	2	0.7
Total	**300**	**100%**

As per the WHO Classification, 51.7% of the people with disabilities had normal BMI. Prevalence of overweight was 17% and obesity 6.7%.

Figure 5.3 Gender distribution of the Primary Care Givers



Most (75.7%) of the primary caregivers were females.

Table 5.23 Age distribution of the Primary Care Givers

Age of the Primary caregiver	Frequency	Percentage
20-29	41	13.7%
30-39	52	17.3%
40-49	52	17.3%
50-59	65	21.7%
60-69	66	22.0%
70-79	20	6.7%
80 and above	4	1.3%
Total	**300**	**100%**

The elderly formed 30% of the primary caregivers.

Table 5.24 Relation of the primary caregivers to the person with disability

Relation	Frequency	Percentage
Parent	112	37.3%
Wife	59	19.7%
Child	49	16.3%
Sibling	34	11.3%
Others	31	10.3%
Husband	15	5%
Total	**300**	**100%**

In more than half (53.7%) of the households the relationship between the person with disability and the primary caregiver was parent-child.

Table 5.25 Duration of disability among the people with disabilities

Duration of disability in years	
Mean	26.85
Median	25
Mode	20
Minimum	0.40
Maximum	75
Standard deviation	1.61

The mean duration of disability was 26.85 years and standard deviation was 1.61 years.

Table 5.26 Duration of caregiving and relation of the primary caregiver

Primary caregiver's relation with the person with disability	Duration of disability		Total
	20 years and more	19 years and less	
Parent	82 (73.2%)	30 (26.8%)	112
Wife	26 (44.1%)	33(55.9%)	59
Child	17(34.7%)	32(65.3%)	49
Sibling	15(44.1%)	19(55.9%)	34
Others	8(25.8%)	23(74.2%)	31
Husband	6(40.0%)	9(60.0%)	15
Total	**154**	**146**	**300**

Among the primary caregivers who were parents of the persons with disabilities, 73.2% gave care for a duration of 20 years and above.

Table 5.27 Prevalence of malnutrition (by MNA) among those with disabilities (based on screening scores)

MNA screening	Frequency	Percentage
Normal	156	52.0%
At risk of malnutrition	119	39.7%
Malnourished	25	8.3%
Total	**300%**	**100%**

According to the Mini Nutrition Assessment (MNA) scale screening scores 8.3% of the people with disabilities were found to be malnourished and 39.7% of them were at risk for malnutrition.

Table 5.28 Prevalence of malnutrition among the people with disabilties (based on the the malnutrition indicator score)

Malnutrition Indicator score	Frequency	Percentage
Normal	120	40.0%
At risk of malnutrition	155	51.7%
Malnourished	25	8.3%
Total	**300**	**100%**

As per the malnutrition indicator score of the MNA scale, 40% of the persons with disability were found to have normal nutritional status, 51.7% were at risk of malnutrition and 8.3% were malnourished.

Table 5.29 Distribution of people with disabilities by number of meals taken in a day

Number of meals	Frequency	Percentage
1 Meal	5	1.7%
2 Meals	31	10.3%
3 Meals	264	88.0%
Total	**300**	**100%**

Most (88%) of the people with disabilities took three meals per day, whereas 1.7% of them took only one meal per day.

Table 5.30 Self perception of nutritional status among people with disabilities

Self perception of nutritional status	Frequency	Percentage
Malnourished	38	12.7%
Uncertain	84	28%
No nutritional problem	178	59.3%
Total	300	100%

Among the 300 people with disabilities, 12.7% viewed their nutritional status as malnourished and 28% were uncertain about their nutritional status.

Table 5.31 Distribution of the people with disabilities by mid-arm circumference (MAC)

Mid-arm Circumference	Frequency	Percentage
< 21 cm	30	10.0%
21 – 22 cm	26	8.7%
≥ 22 cm	244	81.3%
Total	**300**	**100%**

Of the 300 people with disabilities, 81.3% had normal MAC but 10.0% had less than 21 cm as MAC.

Table 5.32 Distribution of the people with disabilties by calf circumference

Calf circumference	Frequency	Percentage
Less than 31 cm	175	58.3%
More than 31 cm	125	41.7%
Total	**300**	**100%**

Of the 300 people with disabilities, 41.7% of them had calf circumference more than 31 cm and 58.3% had calf circumference of 30 cm and below.

Table 5.33 Distribution of the people with disabilties by decline in food intake

Decline in food intake	Frequency	Percentage
Severe decrease	5	1.7%
Moderate decrease	29	9.7%
No decrease	266	88.7%
Total	**300**	**100%**

Among the 300 people with disabilities, 1.7% reported severe decline in food intake over the past 3 months due to loss of appetite, digestive problems, chewing or swallowing difficulties and 9.7% had moderate decrease in food intake due to the same reasons.

Table 5.34 Distribution of the people with disabilities by protein consumption

Protein consumption Markers *	Frequency	Percentage
Nil / 1 yes	220	73.3%
2 yes	80	26.7%
Total	**300**	**100%**

*****1. At least one serving of dairy product (milk, cheese, yoghurt) per day. 2. Two or more servings of legumes or eggs per week. 3. Meat, fish, poultry every day.

None of the people with disabilities consumed meat or fish or poultry every day. Most of them (73.7%) consumed only at least one serving of dairy product (milk, cheese, yoghurt) per day.

Table 5.35 Distribution of people with physical disabilities by their self rate of quality of life

Self rate of quality of life	Frequency	Percentage
Very poor	2	1.0%
Poor	74	36.5%
Neither poor nor good	50	24.6%
Good	76	37.4%
Very good	1	0.5
Total	**203**	**100%**

Of the 203 people with disabilities, 37.4% rated their lives as good quality and 36.5% of the rated their quality of life as poor.

Table 5.36 Description of domain wise scores of quality of life among the people with physical disabilities

Domains	Mean	Median	Standard deviation	Minimum	Maximum
Physical	48.99	50.00	10.76	10.71	71.43
Psychological	50.67	50.00	11.57	25.00	66.67
Social	59.31	58.33	15.89	16.67	75.00
Environmental	61.45	62.50	11.25	28.12	75.00

Among the 203 people with physical disabilities the mean score for physical domain of quality of life was 48.99 and standard deviation was 10.76.

Table 5.37 Distribution of the people with physical disabilities by their satisfaction with health

Satisfaction with health	Frequency	Percentage
Very dissatisfied	2	1.0%
Dissatisfied	69	34%
Neither satisfied nor dissatisfied	24	11.8%
Satisfied	101	49.8%
Very Dissatisfied	7	3.4%
Total	**203**	**100%**

Most (49.8%) of the people with physical disabilities were satisfied with their health and 34% of them were dissatisfied with their health.

Table 5.38 Distribution of people with physical disabilities by their frequency of negative feelings

Frequency of negative feelings	Frequency	Percentage
Never	1	5%
Seldom	14	6.9%
Quite often	66	32.5%
Very often	115	56.5%
Always	7	3.4%
Total	**203**	**100%**

Of the 203 people with physical disabilities, (56.5%) of reported that they get negative feelings very often and 3.4% of them reported having negative feelings all the time.

Table 5.39 Distribution of the primary caregivers of the people with disabilties by their self rating of quality of life

Self rating of quality of life	Frequency	Percentage
Very poor	5	1.7%
Poor	77	25.7%
Neither poor nor good	51	17.0%
Good	166	55.3%
Very good	1	0.3%
Total	**300**	**100**

Most (55.3%) of the primary caregivers of the people with disabilities reported having good quality of life. However, 25.7% of them reported having poor quality of life.

Table 5.40 Description of domain wise scores of quality of life among the primary caregivers

Domains	Mean	Median	Standard deviation	Minimum	Maximum
Physical	41.63	42.85	6.11	17.86	60.71
Psychological	58.59	62.50	9.51	29.17	75.00
Social	65.94	75.00	14.31	16.67	100.00
Environmental	66.27	70.31	11.19	31.25	93.75

Among the 300 primary caregivers, the mean score for physical domain of quality of life was 41.63 and standard deviation was 6.11.

Table 5.41 Distribution of primary caregivers by their satisfaction of health

Satisfaction of health	Frequency	Percentage
Dissatisfied	80	26.7%
Neither dissatisfied nor satisfied	33	11.0%
Satisfied	126	42.0%
Very satisfied	61	20.3%
Total	**300**	**100%**

Most (42.0%) of the primary caregivers of the people with disabilities were satisfied about their health. However, 26.7% were dissatisfied about their health.

Table 5.42 Distribution of primary caregivers of the people with disabilities by their frequency of negative feelings

Frequency of negative feelings	Frequency	Percentage
Never	2	0.7
Seldom	21	7.0%
Quite often	77	25.7%
Very often	195	65.0%
Always	5	1.7%
Total	**300**	**100%**

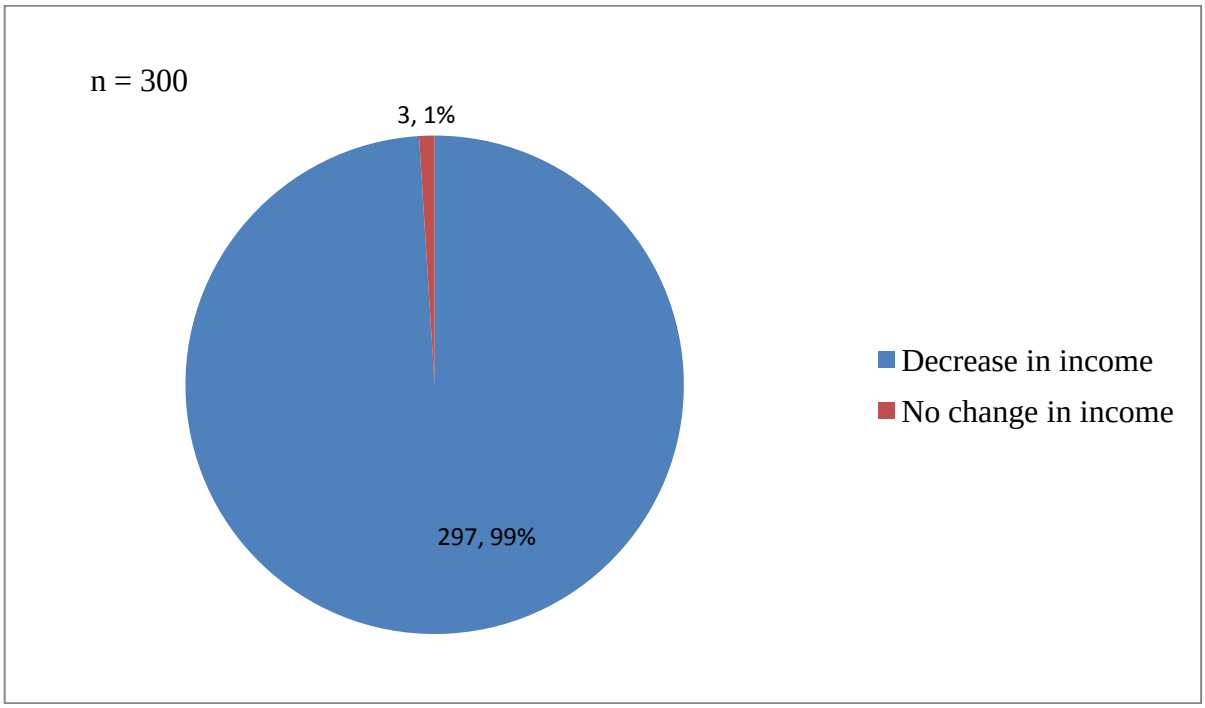
Of the 300 primary caregivers of the people with disabilities, 1.7% had negative feelings always and 65% of them had negative feelings very often.

Table 5.43 Description of domain wise scores of Disability Assessment Schedule(DAS) among the people with disabilities

Domains	Mean	Median	Standard deviation	Minimum	Maximum
Cognition	23.50	5.00	30.52	0	100
Mobility	45.87	56.25	39.05	0	100
Self-care	19.90	0.00	29.36	0	100
Getting along with people	19.611	0.00	26.65	0	100
Household activities	62.23	50.00	30.71	0	100
Work or school activities	81.90	78.57	21.84	0	100
Participation	57.70	58.33	20.37	4.17	100
Overall score	45.21	41.98	18.06	6.60	97.17

The mean overall score for DAS was 45.21 and standard deviation was 18.06.

Figure 5.4 **Change in Income status as a result of health condition (among the persons with diasbility)**



Of the 300 people with disabilities, 297 reported having to work at lower level and earn less money as a result of their health condition.

Table 5.44 **Distribution of the people with disabilities by the number of days in which he/she was totally unable to carry out usual activities in the past one month.**

No. of days	Frequency	Percentage
0	221	73.7%
1-5	6	2.0%
6-10	29	9.7%
11-15	2	0.7%
16-20	9	3.0%
21-30	33	11.0%
Total	**300**	**100%**

Among the 300 people with disabilities, 26.4% were totally unable to carry out usual activities at least for one day in the past one month. However most (73.7%) of them were able to carry out usual activities.

Table 5.45 Distribution of people with visual disabilities by ICF grading of difficulty in seeing

ICF Grading	Frequency	Percentage
Moderate difficulty	10	26.3%
Severe difficulty	14	36.8%
Complete difficulty	14	36.8%
Total	**38**	**100%**

Among the people with visual disabilities, 36.8% of them experienced complete difficulty and equal numbers experienced severe difficulty in seeing.

Table 5.46 Distribution of people with hearing/speech disablities by ICF grading of difficulty in hearing

ICF Grading	Hearing disability		Speech disability		Total	
	Frequency	Percentage	Frequency	Percentage	Frequency	Percentage
Mild	1	2.12%	0	0	1	1.01%
Moderate	13	27.65%	13	25%	26	26.26%
Severe	17	36.1%	20	38.46%	37	37.37%
Complete	16	34.04%	19	36.53%	35	35.35%
Total	**47**	**100%**	**52**	**100%**	**99**	**100%**

Of the 47 people with hearing disability 34.04% of them experienced complete difficulty in hearing and among the people with speech disability, 36.53% experienced complete difficulty in hearing.

Table 5.47 Distribution of the people with disabilities by ICF grading of difficulty in employment

ICF Grading	Frequency	Percentage
No difficulty	1	0.3%
Mild difficulty	2	0.7%
Moderate difficulty	43	14.3%
Severe difficulty	136	45.3%
Complete difficulty	136	45.3%
Not applicable	2	0.7%
Total	**300**	**100**

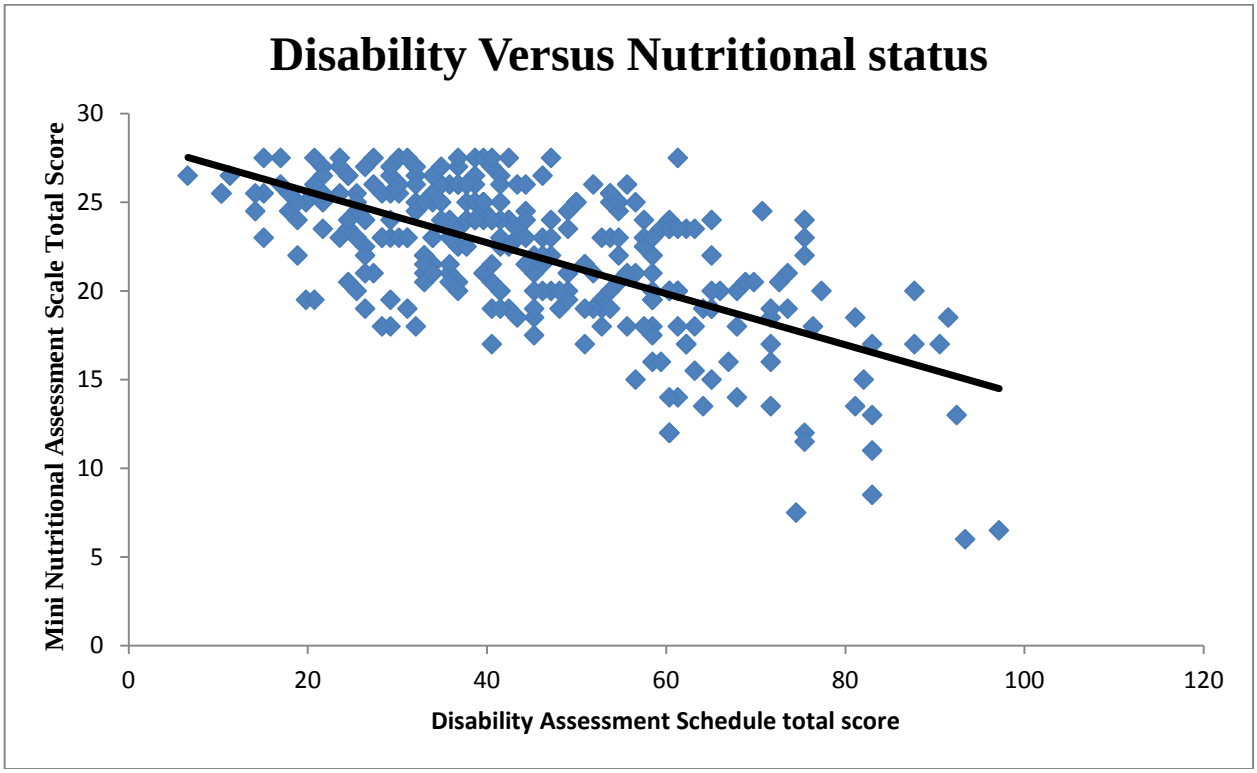
Of the 300 people with disabilities, 90.6% had complete and severe difficulty in employment.

Table 5.48 Distribution of the people with disabilities by ICF grading of difficulty in community life

ICF Grading	Frequency	Percentage
No difficulty	7	2.3%
Mild difficulty	8	2.7%
Moderate difficulty	87	29.0%
Severe difficulty	167	55.7%
Complete difficulty	30	10.0%
Not applicable	1	0.3
Total	**300**	**100%**

Most (55.7%) of the people with disabilities had severe difficulty in participating in community life and 10% had complete difficulty in participating in community life.

Figure 5.5 Correlation between disability and nutritional status



A Pearson's Correlation coefficient was computed to assess the relationship between the severity of disability according to Disability Assessment Schedule (WHO DAS 2.0) scores and malnutrition according to Mini Nutritional Assessment Scale (MNA), Malnutrition indicator scores. There was a negative correlation observed between the two variables,

r = -0.647, n = 300 and p = <0.01. Increase in severity of disability was correlated with reduced nutritional status.

Table 5.49 Effect of socio-economic status on quality of life of people with physical disabilties

Quality Of Life Domains	SES	Mean	Standard Deviation	P Value
Physical	Lower	47.84	11.08	**0.011**
	Middle	51.86	9.63	
Mental	Lower	48.54	11.77	**< 0.001**
	Middle	54.66	10.54	
Social	Lower	56.20	17.11	**< 0.001**
	Middle	66.16	9.9	
Environmental	Lower	59.03	11.38	**< 0.001**
	Middle	66.74	8.73	
Self Rating Of QOL	Lower	1.57	0.496	**0.015**
	Middle	1.74	0.438	
Satisfaction On Health	Lower	1.62	0.48	0.176
	Middle	1.71	0.45	

The effect of socio economic status on the mean scores of the domains of quality of life among those with a physical disability was tested using independent sample t test and the difference between lower and middle socio economic status in all the domains of quality of life and self rating of quality of life was found to be statistically significant; all the p values were <0.05.

Table 5.50 Factors affecting the physical domain of quality of life of people with physical disabilities

Variables		Scores of QOL		Chi Square (p value)	Unadjusted Odds Ratio (Confidence Interval)	Adjusted odds ratio (confidence interval)	P value
		<50	≥50				
Age	≥ 60	42 (60.9%)	27 (39.1%)	**6.639 (0.012)**	**2.167 (1.198 - 3.920)**	1.613 (0.803-3.239)	**0.179**
	<60	56 (41.2%)	78 (58.2%)				
Education	Up to Middle	78 (53.4%)	68 (46.6%)	**5.52 (0.02)**	**2.122 (1.126 - 3.999)**	1.432 (0.661-3.104)	**0.365**
	High and Above	20 (35.1%)	37 (64.9%)				
Occupation	Unemployed	78 (56.9%)	59 (43.1%)	**12.651 (0.001)**	**3.041 (1.628 - 5.678)**	1.881 (0.926-3.823)	**0.081**
	Employed	20 (30.3%)	46 (69.7%)				
Socio-economic status	Lower	75 (53.2%)	66 (46.8%)	**4.467 (0.047)**	**1.927 (1.045 - 3.555)**	1.361 (0.658-2.812)	**0.406**
	Middle	23 (37.1%)	39 (62.9%)				
Cause of disability	Non congenital	91 (52%)	84 (48 %)	**7.047 (0.008)**	**3.250 (1.314 - 8.037)**	**3.025 (1.086-8.425)**	**0.030**
	Congenital	7 (25%)	21 (75%)				
Type of Disability	Visual	19 (5.5%)	10 (34.5%)	**4.028 (0.07)**	**2.285 (1.004 - 5.197)**	2.331 (0.932-5.822)	**0.070**
	Non visual	79 (45.4%)	95 (54.6%)				
DAS Total Score	≥ 45.21	43 (74.1%)	15 (25.9%)	**21.75 (<0.01)**	**4.691 (2.384 - 9.229)**	**3.319 (1.585-6.948)**	**0.001**
	≤ 45.20	55 (37.9%)	90 (62.1%)				

Among the people with physical disabilities, quality of life scores for the physical domain were calculated and categorized based on the median score. (Values below the median were considered to have a poorer quality of life). Chi-square test was performed and odds ratios were calculated. Non congenital causes of disability and more severe levels of disability (Disability Assessemnt Schedule score of 45.21 and above) were found to be significantly associated with poorer quality of life in the physical domain.

Table 5.51 Factors affecting the psychological domain of quality of life of people with physical disabilities

Variables		Scores of QOL		Chi square (p value)	Unadjusted Odds ratio (Confidence Interval)	Adjusted odds ratio (confidence interval)	P value
		<50	≥50				
Age	≥ 60	41 (59.4%)	28 (40.6%)	**6.17 (0.017)**	**2.103 (1.165 - 3.798)**	1.759 (0.874-3.539)	0.113
	<60	55 (41%)	79 (59%)				
Occupation	Unemployed	77 (56.2%)	60 (43.8%)	**13.432 (<0.01)**	**3.175 (1.69 -5.965)**	1.785 (0.870-3.664)	0.114
	Employed	19 (28.8%)	47 (71.2%)				
Socio-economic status	Lower	76 (53.9%)	65 (46.1%)	**8.092 (0.006)**	**2.455 (1.312 - 4.597)**	1.775 (0.869-3.624)	0.115
	Middle	20 (32.3%)	42 (67.7%)				
Cause of disability	Non congenital	90 (51.4%)	85 (48.6%)	**8.715 (0.004)**	**3.882 (1.501 - 10.040)**	**3.412 (1.174-9.916)**	**0.024**
	Congenital	6 (21.4%)	22 (78.6%)				
DAS total Score	≥ 45.21	44 (75.8%)	14 (24.1%)	**26.592 (<0.01)**	**5.62 (2.818 - 11.213)**	**3.048 (1.406-6.609)**	**0.005**
	≤ 45.20	52 (35.85%)	93 (64.13%)				
Malnutrition indicator score	Malnourished and at risk	56 (60.21%)	37 (39.7%)	**11.501 (0.001)**	**2.659 (1.5 – 4.677)**	1.364 (0.680-2.733)	0.382
	Normal	40 (36.36%)	70 (63.63%)				

Among the people with physical disabilities, Non congenital causes of disability and more severe levels of disability (Disability Assessemnt Schedule score of 45.21 and above) were found to be significantly associated with poorer quality of life in the psychological domain.

Table 5.52 **Factors affecting the social domain of quality of life of people with physical disabilities**

Variables		Scores of QOL		Chi square (p value)	Unadjusted Odds ratio (Confidence interval)	Adjusted odds ratio (confidence interval)	P value
		<58.33	≥58.33				
Age	≥ 60	32 (46.4%)	37 (53.6%)	**7.148 (0.012)**	**2.267 (1.237 - 4.156)**	**1.927 (0.863-4.302)**	**0.109**
	<60	37 (21.4%)	97 (72.4%)				
Education	Till Middle	57 (39.0%)	89 (61%)	**5.912 (0.02)**	**2.402 (1.171 -4.926)**	**1.317 (0.512-3.385)**	**0.567**
	High and above	12 (21.1%)	45 (78.9%)				
Occupation	Unemployed	59 (43.1%)	78 (56.9%)	**15.469 (<0.01)**	**4.236 (1.995 - 8.995**	**2.099 (0.853-5.164)**	**0.107**
	Employed	10 (15.2%)	56 (54.8%)				
Socio-economic status	Lower	61 (43.3%)	80 (56.7%)	**17.69 (<0.001)**	**5.147 (2.281- 11.61)**	**4.092 (1.55-10.804)**	**0.004**
	Middle	8 (12.9%)	54 (87.1%)				
Marital Status	Single	47 (41.6)	66(58.4 %)	**6.566 (0.012)**	**2.201 (1.19 - 4.47)**	**3.253 (1.474-7.181)**	**0.003**
	Married	22 (24.2%)	68 (75.6%)				
Cause of disability	Non congenital	63 (36%)	112 (64%)	**2.284 (0.196)**	**2.062 (0.794 -5.354)**	**1.166 (0.321-4.234)**	**0.816**
	Congenital	6 (21.4%)	22 (78.6%)				
Severity of disability	≥ 45.21	38 (65.5%)	20 (34.5%)	**35.972 (<0.001)**	**6.987 (3.57-13.674)**	**4.824 (2.004-11.609)**	**<0.001**
	<45.21	31 (21.4%)	114 (78.6%)				

Among the 203 people with physical disabilities, lower socio-economic status, being single and severe disability with Disability Assessment schedule score of 45.21 and above were significantly associated with poorer quality of life in social domain.

Table 5.53 **Factors affecting the environmental domain of quality of life of people with physical disabilities**

Variables		Scores of QOL		Chi square (p value)	Odds ratio (95% CI)	Adjusted odds ratio	P value
		<62.50	**≥62.50**				
Occupation	Unemployed	81 (59.1%)	56 (40.9%)	**18.086 (<0.01)**	**3.857 (2.034 –7.314)**	**2.404 (1.181-4.894)**	**0.016**
	Employed	18 (27.3%)	48 (72.7%)				
Socio-economic status	Lower	83 (58.9%)	58 (41.1%)	**18.837 (<0.01)**	**4.114 (2.126 –7.963)**	**3.371 (1.788-7.702)**	**<0.001**
	Middle	16 (25.8%)	46 (74.2%)				
Cause of disability	others	91 (52 %)	84 (48 %)	**5.303 (0.025)**	**2.708 (1.133-6.477)**	**2.142 (0.792-5.793)**	**0.133**
	congenital	8 (28.6%)	20 (71.4%)				
DAS Score	≥ 45.21	45 (77.6%)	13 (22.4%)	**26.99 (<0.01)**	**5.833 (2.888 –11.78)**	**3.607 (1.622-8.023)**	**0.002**
	≤ 45.20	54 (37.2%)	91 (62.8%)				
Malnutrition indicator score	Malnourished and at risk	59 (63.4%)	34 (36.6%)	**14.788 (<0.01)**	**3.037 (1.711 –5.389)**	**1.953 (0.991-3.847)**	**0.053**
	Normal	40 (36.4%)	70 (63.6%)				

Among the 203 people with physical disabilities, being unemployed, lower socio-economic status and severe disability with Disability assessment schedule score of 45.21 and above were significantly associated with poorer quality of life in environmental domain.

Table 5.54 **Factors affecting the physical domain of quality of life of primary caregivers**

Variables		Scores of QOL		Chi square value (p value)	Unadjusted Odds ratio (Confidence interval)	Adjusted odds ratio (confidence interval)	P value
		<42.85	**≥42.85**				
Age of caregiver	≥ 60	51 (56.7%)	39 (43.3%)	**7.071 (0.011)**	**1.962 (1.19 - 3.234)**	**1.764 (1.007-3.088)**	**0.047**
	<60	84 (40%)	126 (60%)				
Sex of caregiver	Female	101 (44.5%)	126 (55.5%)	0.097 (0.788)	0.919 (0.542-1.561)	1.079 (0.605-1.925)	0.796
	Male	34 (46.6%)	39 (53.4%)				
Relation with the person with disability	Parent	60 (53.6%)	52 (46.4%)	**5.305 (0.023)**	**1.738 (1.084-2.788)**	1.350 (0.800-2.281	0.261
	Others	75 (39.9%)	113 (60.1%)				
Socio-economic status	Lower	104 (49.3%)	107 (50.7%)	**5.287 (0.023)**	**1.819 (1.089- 3.037)**	**1.614 (0.942-2.766)**	**0.81**
	Middle	31 (34.8%)	58 (65.8%)				
DAS total score	≥ 45.21	75 (55.1%)	61 (44.9%)	**10.35 (0.002)**	**2.131 (1.34 - 3.389)**	**2.042 (1.258-3.314)**	**0.004**
	<45.21	60 (36.6%)	104 (63.4%)				

Among the 300 primary caregivers of the people with disabilities, caregiver being elderly and severe disability with a Disability Assessment Schedule score being 45.21 and above were significantly associated with poor quality of life in physical domain.

Table 5.55 **Factors affecting the psychological domain of quality of life of Primary caregivers**

Variables		Scores of QOL		Chi square (p value)	Odds ratio (Confidence interval)	Adjusted odds ratio (p value)	P value
		<62.50	≥ 62.50				
Sex of caregiver	Female	111 (48.9%)	47 (64.4)	3.927 (0.058)	1.730 (1.003- 2.984)	2.247 (1.19-4.23)	0.012
	Male	26 (35.6%)	47 (64.4%)				
Age of caregiver	≥ 60	59 (65.8%)	31 (34.4%)	**20.497 (<0.01)**	**3.221 (1.92 - 5.402)**	**3.907 (2.159-7.07)**	**<0.001**
	<60	78 (37.1%)	132 (62.9%)				
Socio-economic status	Lower	111 (52.6%)	100 (47.4%)	**13.806 (<0.01)**	**2.69 (1.582-4.573)**	**2.076 (1.64-3.705)**	**0.013**
	Middle	26 (29.2%)	63 (70.8%)				
Relation of caregiver to person with disability	Parent/Child	88 (54.7%)	73 (45.3%)	**11.323 (0.001)**	**2.214 (1.389-3.529)**	**1.804 (1.075-3.027)**	**0.025**
	Others	49 (35.3%)	90 (64.7%)				
DAS total score	≥ 45.21	82 (60.3%)	54 (39.7%)	**21.453 (<0.01)**	**3.009 (1.877-4.827)**	**2.787 (1.423-5.461)**	**0.003**
	<45.21	55 (33.5%)	109 (50.7%)				

Among the 300 primary caregivers of the persons with disability, age of the caregiver, socio-economic status, relation to the persons with disability and severity of the disability were significantly associated with psychological domain of quality of life.

Table 5.56 **Factors affecting the social domain of quality of life of primary caregivers domain**

Variables		Scores of QOL		Chi square (p value)	Odds ratio (95% CI)	Adjusted odds ratio (confidence interval)	P value
		<75.00	≥ 75.00				
Sex of caregiver	male	13 (17.8%)	60 (82.2%)	**12.968 (<0.001)**	**3.203 (1.663 - 6.169)**	**4.317 (2.005- 9.294)**	**<0.001**
	female	93 (41%)	134 (59 %)				
Age of caregiver	≥ 60	45 (50%)	45 (50%)	**12.104 (0.001)**	**2.443 (1.468 - 4.065)**	**3.298 (1.775-6.131)**	**<0.001**
	<60	61 (29%)	149 (71%)				
Socio-economic status	lower	92 (43.6%)	119 (56.4%)	**21.282 (<0.001)**	**4.142 (2.201 – 7.793)**	**2.95 (1.499-5.812)**	**0.002**
	middle	14 (15.7%)	75 (54.3%)				
Relation to disabled	parent/child	68 (42.2%)	93 (57.8%)	**7.246 (0.008)**	**1.943 (1.194 - 3.162)**	**1.508 (0.864-2.632)**	**0.149**
	others	38 (27.3%)	101 (72.7%)				
DAS total score	≥ 45.21	69 (50.7%)	67 (49.3%)	**25.829 (<0.001)**	**3.535 (2.15 - 5.811)**	**1.261 (0.613-2.593**	**0.528**
	<45.21	37 (22.6%)	127 (77.4%)				

Among the 300 primary caregivers of the persons with disability, Female and elderly caregivers and lower socio-economic status were significantly associated with poorer quality of life in social domain.

Table 5.57 **Factors affecting the environmental domain of quality of life of primary caregivers**

Variable		Scores of QOL		Chi-square	Odds ratio (Confidence interval)	Adjusted odds ratio	p Value
		<70.31	≥ 70.31				
Sex of the caregiver	Female	124 (54.6%)	103 (45.4%)	**7.984 (0.007)**	**2.176 (1.26 -3.756)**	**2.712 (1.431-5.138)**	**0.002**
	Male	26 (35.6%)	47 (64.4%)				
Age of caregiver	≥ 60	59 (65.5%)	31 (34.4%)	**12.44 (0.001)**	**2.489 (1.49 -4.159)**	**2.987 (1.637-5.448)**	**<0.001**
	<60	91 (43.3%)	119 (56.7%)				
Socio-economic status	Lower	122 (57.8%)	89 (42.2%)	**18.397 (<0.001)**	**2.986 (1.768-5.044)**	**2.313 (1.31-4.09)**	**0.004**
	Middle	28 (31.5%)	61 (68.5%)				
Type of relation to disabled	Parent/Child	94 (58.4%)	67 (41.6%)	**9.773 (0.003)**	**2.079 (1.311-3.299)**	**1.649 (0.981-2.771)**	**0.059**
	Others	56 (40.3%)	83 (59.7%)				
DAS total score	≥ 45.21	90 (66.2%)	46 (33.8%)	**26.04 (<0.001)**	**3.391 (2.106 5.462)**	**3.485 (2.043-5.944)**	**<0.001**
	<45.21	60 (36.6%)	104 (63.4%)				

Among the 300 primary caregivers, factors which were significantly associated with environmental domain of quality of life were caregiver being female and elderly, lower socio-economic status, caregiver being a parent or child and Disability Assessment Schedule score being 45.21 and above.

Table 5.58 Factors affecting the nutritional status of people with disabilities

Variable		Malnourished and at risk	Normal	Chi square (p value)	Unadjusted Odds Ratio (Confidence interval)	Adjusted odds ratio (Confidence interval)	P value
Occupation	Unemployed	152 (68.2%)	71 (31.8%)	**24.113 (<0.001)**	**3.746 (2.176-6.449)**	1.635 (0.859 -3.094)	0.135
	Employed	28 (36.4%)	49 (63.6%)				
Marital Status	Single	129 (67.9%)	61 (32.1%)	**13.457 (<0.001)**	**2.446 (1.509-3.965)**	**1.831 (1.013-3.311)**	**0.045**
	Married	51 (46.4%)	59 (53.6%)				
Cause of disability	Congenital	69 (79.3%)	18 (20.7%)	**19.038 (<0.001)**	**3.523 (1.964-6.318)**	0.509 (0.243-1.066)	0.073
	Non congenital	111 (52.1%)	102 (47.2%)				
More than one disability	Yes	95 (80.5%)	23 (19.5%)	**34.087 (<0.001)**	**4.714 (2.745-8.093)**	**2.127 (1.093-4.136)**	**0.026**
	No	85 (46.7%)	97 (53.3%)				
Benefit from disability pension	Yes	114 (71.7%)	45 (28.3%)	**19.289 (<0.01)**	**2.879 (1.785-4.643)**	**2.018 (1.138-3.580)**	**0.016**
	No	66 (46.8%)	75 (53.2%)				
DAS Score	≥ 45.21	116 (85.3%)	20 (14.7%)	**66.32 (<0.001)**	**9.062 (5.13-16.00)**	**6.106 (3.194-11.67)**	**<0.001**
	≤ 45.20	64 (39%)	100 (61%)				

Among the 300 persons with disability, factors which were significantly associated with malnutrition and at risk for malnutrition are being single, having more than one type of disability, more severe disability (score of 45.21 and above in Disability Assessment Schedule).

Table 5.59 Factors affecting severity of disability of people with disabilities

Variable		More Severe	Less severe	Chi Square (p value)	Unadjusted odds ratio (confidence interval)	Adjusted odds ratio (Confidence interval)	P value
Age	**≥60**	38 (44.7%)	47 (55.3%)	0.019 (0.898)	0.965 (0.583-1.599)	**1.449 (0.768-2.734)**	**0.252**
	<60	98 (45.6%)	117 (54.4%)				
Sex	**Female**	83 (53.2%)	73 (46.8%)	**8.126 (0.005)**	**1.952 (1.23 – 3.099)**	**2.275 (1.295-3.996)**	**0.004**
	Male	53 (36.8%)	91 (63.2%)				
Socio-economic status	**Lower**	103 (48.8%)	108 (51.2%)	3.479 (0.075)	1.618 (0.974-2.689)	1.940 (1.049-3.588)	0.035
	Middle	33 (37.1%)	56 (62.9%)				
Type Of Disability	**Mental**	78 (80.4%)	19 (19.6%)	**71.179 (<0.01)**	**10.26 (5.708-18.45)**	**9.013 (3.956-20.53)**	**<0.001**
	Physical	58 (28.6%)	145 (71.4%)				
More than one disability	**Yes**	84 (71.2%)	34 (28.8%)	52.459 (<0.01)	**6.176 (3.702-10.30)**	**3.203 (1.599-6.413)**	**<0.001**
	No	52 (28.6%)	130 (71.4%)				
Cause of disability	**Non congenital**	50 (57.5%)	37 (42.5%)	7.285 (0.008)	**1.996 (1.204-3.308)**	**1.979 (0.824-4.756)**	**0.127**
	Congenital	86 (40.4%)	127 (59.6%)				
Duration of disability in years	**≤ 24**	62 (39.5%)	95 (60.5%)	4.537 (0.037)	**1.643 (1.039-2.599)**	**1.888 (1.054-3.380)**	**0.033**
	>24	74 (51.7%)	69 (48.3%)				

Among the 300 persons with disabilities, the factors which were significantly associated with more severe disability (Disability Assessment score 45.21 and above) were, being a female, belonging to lower socio-economic status, presence of mental disability and having more than one disability.

RESULTS OF THE FOCUS GROUP DISCUSSIONS

FINDINGS OF THE FOCUS GROUP DISCUSSION AMONG PEOPLE WITH DISABILITIES

The discussion was targetted to gather information on the following topics- Social problems encountered by the people with disabilities, barriers and hindrances faced by the people with disabilities, negative feelings associated with disability, impact of disability on family, quality of life of the people with disabilities and factors affecting it and difficulties associated with participation

DEMOGRAPHICS OF THE PARTICIPANTS

10 persons with disabilities were invited and only 8 participated in the study. All of them had locomotive disability. After obtaining informed consent the discussion was started.

Age distribution: The minimum age was 24 years, maximum 65 years and mean age was 46 years.

Sex distribution: Except for 2 participants rest were males

Marital status: 2 of them were married. Rest were single.

Education status: The minimum years of education was 5 and maximum was 12.

Employment status: All were involved in some income generating activity

OUTCOME 1: SOCIAL PROBLEMS ENCOUNTERED BY PEOPLE WITH DISABILITIES

All the participants with disability shared the social discrimination, stigma and oppression they experienced in every sphere of social life. Especially in their attempts to get a job,while travelling in public transport and participating in community festivals and

parties, they said the reproach was excruciatingly poignant. On the topic of stigma, one of the male participants said,

" *In villages, people don't hesitate to call us as mute (oomai), blind (kurudu), lame (nondi)". Eventhough these abusive words are obsolete theoretically and euphemistic expressions have taken their places, they are still used just to disgrace and shame us. Such offensive labellings remain etched in memory causing deep feelings of discrimination. Some even dare to judge us declaring that the disability is due to the sins we've committed due to our pride and arrogance (thimiru)".*

The young persons with disabilities expressed their worries of their marriages being delayed and their doubts whether they would be able to enjoy such bliss of life inspite of their disabilities. Of great concern was an unmarried female participant who was reluctant to talk about motherhood or married life since it was never going to happen in her life. When discussing about the societal reactions to a person with disability, a young man using wheel chair said,

" *Our very entry into a room on a wheel chair or walking stick provokes humiliating gazes and comments. Even our own relatives feel ashamed to be standing next to us. Sometimes we do wonder whether we are human beings or animals*."

Participants associated these reactions to their disability status, use of aids and also socioeconomic status. They mentioned that a person having a disability but having wealth, rich legacy or money was less stigmatized. Therefore empowering them economically could protect them against discrimination and stigma. Having enough money would generate respect among others. On the neighbourhood's reaction to a person's disability, a female participant said,

" *Some think that their images may be affected if they come and talk to a person in a wheel chair. Our close relatives who were once loving and caring, now ignore us after the onset of the disability. This type of treatment from our own relatives comes as a shock to us".*

Greater degrees of discrimination and prejudice were experienced in work places, community functions and educational institutions. This was evident from a person's statement about his work place.

"*When I ask for the right amount of salary as paid to people without disabilities at my workplace, I am told that for my level of disability, the present salary is enough and the reason that I am asking for more salary is due to my rebellious spirit"*

On how the families treat a person with disability, a young man said,

"*Even in our own families we feel as if we are ostracised when our parents or other relatives say that we are a great burden to them with no finanacial contribution from our side . Such remarks infuriate us and when we express our anger we hear more hurtful comments on how we should remain humble because of our disability and accept disability as a punishment from God. These trying situations make us feel that we are the most unprivileged ones deprived of fundamental rights and basic human rights as well".*

Social problems discussed by the persons with disability revealed that stigma and discrimination are the two main stumbling blocks hindering them from leading a normal life and not the physical impairments as such. They asserted that most of the time when normalcy has returned and resilience has made them forget their disabilities, another ridiculous stare, a mockery, an absurd comment starts a vicious circle. Empathy, superstition, old beliefs, conservative ideas and ignorance formed reasons for stigma.

OUTCOME 2: BARRIERS AND HINDRANCES FACED BY PEOPLE WITH DISABILITIES

All the persons with disability had faced similar barriers while travelling in public transport. Most of the drivers and conductors refuse to take them in even if they could climb in. This resulted in them having to travel by more expensive modes of travel such as auto rickshaws and motor bikes. Another difficulty was that people with disabilities had to get ready well ahead of time since all these processes took longer than for a person without disabilities. Most of the times any mode of travel involves troubling others. On difficulties faced due to barriers by a person with disability at home and public places, a person with spinal cord injury said,

" *Performing simple tasks such as cooking and doing household chores becomes troublesome since our environment is not friendly for us. Carrying water in pitchers is the most important household chore in a drought prone area like Vellore. But even that job cannot be performed by most of us because of fear and embarrassment. This is an additional burden we give to our families. None of our toilets are suited for us since none of our houses have assisted living facility. So we end up practising open air defecation which is extremely uncomfortable. Availability of a western toilet in any public place like a hospital is considered a luxury for us".*

OUTCOME 3: NEGATIVE FEELINGS ASSOCIATED WITH DISABILITY

Many of the participants became emotional when sharing their negative feelings. Some of the negative feeling expressed by the participants were,

" Each time *the absolute truth that I can never walk normally again sinks in, I go into a quiet state of depression*"

"*If the disability was congenital I think I would have coped better. I get dreams of becoming normal miraculously*".

"*Most of the time I don't even remember that I have a disability until a person calls me disabled or uses insulting terms. I am cheerful until my family reminds me of my disability and tell me that if I were normal, I would have been earning right now*"

There were mixed reactions of anger, frustration and gloom among the participants on sharing their negative feelings associated with disability

OUTCOME 4: IMPACT OF DISABILITY ON FAMILIES

When asked about the impact of disability on families, most of the participants brought up the issues of income and employment. They expressed that a stable income from a person with disability determines how they get treated in their families. Some of the comments were,

"*Only if we earn money we can enjoy good food and care at home without any feeling of guilt. Some of our family members are depressed and sad about our disability, thinking how it happened and wondering what a lot of difference it would have made if we were normal. Our caregivers consider us as liabilities*".

"*Even our own family members think that we are putting on an act when we tell them that we get tired easily on doing simple chores and that we have difficulty in performing certain activity. They assume we pretend since we are lazy. No one, not even doctors or our own parents and spouses understand the nature of our illness. Sometimes we wish to go to certain places but our families are not willing to take us due to the difficulties experienced in transport. Most of the time it is our family members who make us feel*

worthless. They make us feel that moving around in a wheelchair is a shameful, disgusting and detestable activity"

OUTCOME 5 : QUALITY OF LIFE OF PEOPLE WITH DISABILITY AND FACTORS AFFECTING IT

When asked about quality of life of persons with disabilities, little was mentioned about the physical impairment as a cause of poor quality of life. Most of them associated good quality of life with employment and income. This was evident from the following comments.

" *I wish I could do my daily activities on my own and that would dramatically improve my quality of life".*

"Earning money for the family is the most important factor contributing to good quality of life. Disability is never a problem if we have enough money".

"*Our quality of life is worsened by the treatment at government offices where bribe, the white collar crime rears its ugly head . Despite our difficulties in transport we brave travelling long distances to employment offices, only to get turned down by reasons such as seniority, percentage of disability and the need for recommendation letters from an influential person. If we were able to fullfil all these criteria ,would we be that desperate for a job*?"

"*It will be considered a miracle if a person with disability gets a job in government services. There is inadequate legislations on providing equal job oppurtunities for a person with disability. Even if we get a job we are treated very differently and our colleagues consider us as their competitors and not as their facilitators . They can't accept the fact that we get equal salary despite having a disability. In private enterprises,*

when we demand an equal pay, we get abusive replies that being employed itself is a gift for a person with disability like us and that for the amount of disability we should get only less pay as compared to others".

OUTCOME 6: DIFFICULTIES ASSOCIATED WITH PARTICIPATION

When asked about the difficulties associated with participation, the reasons told by one of the participants were,

"*We don't have a stable income. Because of our poor socio economic status, transport problems and sexual impairments we cannot get married. So how can we imagine that we would get opportunities to participate in social events*".

FINDINGS OF THE FOCUS GROUP DISCUSSION AMONG THE PRIMARY CAREGIVERS:

The topics covered in the focus group discussion among primary caregivers were- Quality of life of primary caregivers and factors affecting it, frequency of negative feelings among primary caregivers, capability of primary caregivers to provide care for the person with disability, types of disabilities and associated difficulties in caregiving, relation with person with disability and caregiving and satisfaction in caregiving.

DEMOGRAPHICS OF THE PARTICIPANTS

12 primary caregivers of people with various disabilities were invited for the discussion but only 9 turned up. After obtaining informed consent the discussion was started.

Age Distribution: The minimum age was 25 years and maximum age was 60 years.

Sex Distribution: Except for one participant all were females

Relation To Disabled:3 were spouses of the disabled and the rest were parents

Type Of Disability: 3 of them cared for persons with mental disability and the rest cared for persons with physical disability

Employment Status:All of them were employed in some income generating activity

OUTCOME 1: QUALITY OF LIFE OF PRIMARY CAREGIVERS AND FACTORS AFFECTING IT

The overall discussion with the primary caregivers revealed a depressing state and several of them had painful anecdotes to relate. When asked about their quality of life, everyone had a similar response,

"*Our quality of life can never be on par with normal family members. Only if the physical impairment and level of disability of our family member improves, then we can think of any improvement in our quality of life. We really feel let down when people start associating our circumstances with the sins we committed (enna paavam pannuniyo). The days in which our neighbours laud us for the love and care we bestow on our disabled family member are the only days that are filled with joy and happiness*."

The caregivers who were wives of persons with disabilities had another concern. One of them said,

"*People question our fidelity when they come to know that our spouses are disabled. All our husbands have delusions of our faithfulness at one point of time or the other*" .

Helping the person with disabiltiy to carry on everyday normal activities of life such as urinating and defecating drastically reduces the caregivers' quality of life. Factors which can improve the caregivers' quality of life were listed out and they were,

1. A stable job for the person with disability

2. The person with disability's capability to perform their daily activities
3. Sanction of loan to start a meaningful income generating activity
4. Means to pay back their debts
5. The person with disability becomimg more productive and active in their lives

OUTCOME 2: FREQUENCY OF NEGATIVE FEELINGS AMONG PRIMARY CAREGIVERS

The costs related to disability such as medical expenses, purchase of aids, marginalization from services, physical inaccesibility push families into poverty. Many of the families have obtained loans from relatives and neighbours. Since the persons with disability are never going to be fully functional, repaying of loans becomes impossible. The community thus ends up abhoring the disabled families. Such circumstances result in seclusion of families with a person with disability from the community and caregivers get depressed at the uncertainity of situations. Going to festivals and community activities are considered rare among the caregiver population since any one in the community can disgrace them with ease. If they have an argument, people comment by saying that because of their arrogance, their child has a disability. Such comments hurt the caregivers beyond measure. Another major problem faced by caregivers is discrimination faced by their children in other houses. A child from a house of a person with disabiltiy is not allowed to enter a house built according to 'Vastu Sashram'. Some say children from houses of persons with disability bring bad luck (ketta sagunam). They are considered as signs of bad omen. Many people never think twice before talking. Some even go to the extent of saying " *Why don't you enrol your son in an orphanage or a foster home?. He is abnormal and he can't live with you*".

The caregivers expressed that all persons with disability are humans and they deserve love, care and affection. A mother of child with intellectual disability said,

"Having an impairment does not mean we will stop loving them. We treat them as equal but no one understands such a relationship."

Some caregivers shared unpleasant events they experienced even in health care settings where physicians and nurses too don't understand their situation. A mother of two children with disabilities said

"*Even healthcare workers say that we pretend to be poor. They also comment that having a disability in the family should not be used to create pity".*

The general comment among the caregivers on the way they were treated in hospitals was,

"Many healthcare staff do not understand the plight we go through in our everyday lives".

OUTCOME 3: CAPABILITY OF A PRIMARY CAREGIVER IN CARING FOR A PERSON WITH DISABILITY

All of the caregivers undergo much difficulty in going for work but there is no other source of income except their work.A mother of a child with motor disability said,

" *We cannot take up occupations of our choice. We can only involve in part time and simple jobs in order to return home to take care of the person with disability*".

When the wives of persons with disability were asked about how they were able to take care of household and work activities, they said,

" *In the beginning multitasking was strenous but we have got accustomed to it. But where ever we are, we cannot stop thinking about the person with disability being alone at home. Our daily routine includes waking up very early in the morning well ahead of others, finishing household chores, giving a bath and helping the person with disability to carry out his other activities of daily living and then getting ready for work. We return from work by noon to continue the chores".*

When a mother of two children with disabilities was asked about the health of caregivers, she said,

"*There is no question of us falling sick and lying in house because there is no one to take care of us. We are the caregivers in the house. Who is there for us ?"*

OUTCOME 4: TYPES OF DISABILITY AND ASSOCIATED DIFFICULTIES

All the caregivers unanimously agreed that people with physical disabilities are the most tough to take care of. It demands physical and mental exertion since it involves laborious efforts in performing daily tasks, travel and self care.

Taking care of the persons with mental disabilities and persons with speech impairment is relatively easy because even if they do something hurtful the caregivers can forgive them easily owing to their mental retardation and poor communication levels. A wife of a person with physical disability summarized the problems faced in taking care of a person with physical disability,

"*The people with physical disabilities are the tough lot. They become angry very easily and pick fights with us for simple reasons. They are fussy and demand a lot. They never seem to understand the trauma we undergo because of their condition. Not understading*

our poverty , they demand expensive things. We have to compromise a lot for them and forgo our ego if we want a quiet family life".

OUTCOME 5: RELATION WITH THE PERSON WITH DISABILITY AND CAREGIVING

Even if there are potential male caregivers in the house, it is invariably the female who is given the role of caregiving, especially in cases of children with disability. The general consensus among the caregivers was, mostly spouses and parents only do the role of caregiving.

OUTCOME 6: SATISFACTION IN CAREGIVING

A mother of child with intellectual disability explained her dissatisfaction in caregiving due to the environemental barriers like this,

"*Even if we give excellent care, the environment disappoints us a lot. Like in the case of children with disability, there is a rehabilitation school for them half an hour distance from home but due to transport difficulties and as accompanying them involves the loss of a day's labour we hardly take them there despite knowing it to be beneficial to them"*

As caregivers, they are eligible for simple government jobs such as sweepers in government offices but normal people get those jobs by offering bribes or through recommendation.

As a concluding message all the caregivers agreed with the following statement by the mother of a young girl with physical disability, "*In the midst of all these hurdles and sorrows in our lives, we love our family member with disability more than the normal members and derive extreme satisfaction in taking care of them.*

6. DISCUSSION

This study assessed the quality of life, nutritional status, severity of disability and functional status among the people with disabilities and the quality of life among their primary caregivers in a rural south Indian population.

In Kaniyambadi block, the elderly constitute 13.1% of the general population. In this study 28.3% of the people with disabilities were elderly. This is expected since the elderly have more physical impairment with advancing age making them more susceptible to disability.

Among the people with disabilities in this study, there were nearly equal number of males and females - 48% were females and 52% were males. As per the health information system of the Community Health Department, CMC Vellore, hindus constitute 96%, christians 2.4% and muslims 1.7% in the Kaniyambadi block. The proportions in our study population was 93% hindus, 6% christians and 1% muslims which is similar to that of the block. Based on the inclusion criteria, all the study population were 18 years and above. What is striking is that 44.7% of the people with disabilities remained single and 2.7% were seperated or divorced. Abu-Habib in her book on disabled women in middle east observed that being disabled reduces the chances of getting married, due to the impairment, loss of economic productivity and fear of the children being born with the same disability (113). This could explain the high proportion of the disabled remaining single.

Among the people with disabilities, 47.3% were literate. This contrasts the 74.04% literacy rate of India (215). This is inspite of the scholarships and reservations the Indian government has awarded for persons with disabilities. In the qualitative part of our study people with disabilities and their caregivers both expressed discontent with the schemes offered by the government due to the corruption in the system and expectation of bribes

even from people with disabilities. In addition, schemes which are available such as schools for intellectually disabled were considered as difficult to utilize due to inaccessibility and travel constraints.

Among the people with disabilities, 74.3% were unemployed. O'Donnell explains the reasons for unemployment among people with disabilities as the physical impairment, difficulty in transport, incentives, difficulty in finding a job that suits the disability and the employers finding the people with disabilities to be unfit for work (90). In the qualitative component of our study, participants expressed stigma and discrimination in work place. To make matters worse, most of the participants who went for work they were paid less for the amount of work they did. This resulted in most of them tending to start their own petty business or do part time jobs that would suit their impairment. This could explain most of the unemployment.

The total monthly family income of the people with disabilities were classified according to the modified kuppusamy's socio-economic status classification and 35% of the households lived on Rs.1601-4809.

Of the people with disabilities, none belonged to upper socio-economic status and 70.3% of the people with disabilities fell in the lower socio-economic status as per the modified kuppusamy's scale. These figures are markedly different from the information in the Health information system of community health departmentwhich reports that 24.7% of the population belong to lower socio-economic status and 51.5% belong to middle socio-economic status. The vast disparity between the socio-economic status of the study population and the general population can be explained by the povery – disability cycle. Elwan in her report on 'Poverty and disability' has noted that knowledge on poverty and disability is limited in developing countries. This is attributed to the fact that there is

paucity of literature on disability and existing knowledge is derived from censuses and surveys which focus only on the prevalence (63).

In this study the most common impairment found was motor (41.97%), followed by hearing/ speech (16.05%), intellectual (13.76%) and psychiatric (10.55%). In the global burden of diseases report 2004, hearing loss followed by refractive errors were listed as leading disabling conditions causing moderate and severe disability (82).

In this study, chronic diseases contributed to 35.3% of the disabilities and congenital conditions to 29% of the disabilities. In the global burden of disease study, non communicable diseases contributed to 40.9% of the disability adjusted life years (83).

Among the 300 people with disabilities, only 53% of them benefitted from disability pension scheme. In the state of Tamil Nadu, disability pension is given for physically handicapped persons with more than 50% disability and any blindness. They are entitled for a total of Rs. 400 per month (72).

Among the 203 people with physical disabilities, 37.9% of them rated their quality of life as good. Albrecht and Devlieger in their interviews with 153 disabled persons found that 54.3% of them have excellent quality of life. Since there is lack of studies on quality of life of persons with disbility in developing nations, these prevalences cannot be compared.

In our study, the difference between lower and middle socio-economic status and all the domains of quality of life were found to be statistically significant with all the pvalues <0.05. Barnes in his report on institutional discrimination against disabled people observed that people from higher socio-economic status were less affected by disability as compared to people from lower socio-economic status, since lower socio-economic status means involving in work that require physical exertion. This results in unemployment, perishment and social death (91). Employment status and inturn socio-economic status

adversely affecting the quality of life among the people with disabilities has been well established in literature (188). This could have contributed to the difference in quality of life scores among the middle and lower socio-economic status groups in our study.

In our study, factors which were significantly associated with poor quality of life in physical domains of people with physical disabilities were the presence of non congenital cause of disability -Adjusted OR 3.025, (95% CI 1.086-8.425) and p value 0.001 and more severe disability (Disability Assessement Schedule score of 45.21 and above)- Adjusted odds ratio 3.319, (95% CI 1.585 – 6.948) and p value 0.030. In psychological domains, presence of non congenital causes of disability- Adjusted odds ratio 3.412, (95% CI 1.174 – 9.916) and p value 0.024 and more severe disability (Disability Assessement Schedule score of 45.21 and above)- Adjusted odds ratio 3.048, (95% CI 1.406 – 6.609) and p value 0.005 were found to be significantly associated with poor quality of life. Amundson et al observed that apart from severity of disability, getting used to a disease also affects quality of life. This is due to the fact that late onset disability shatters the education and employment activities which were done earlier when the person was normal (187).

Among the people with physical disabilities, factors that were significantly associated with poor quality of life scores in social domain were lower socio economic status- Adjusted odds rato 4.092, (95% CI 1.55 – 10.804) and p value 0.004, being single- Adjusted odds ratio 3.253, (95% CI 1.474 – 7.181) and p value 0.003 and more severe disability (Disability Assessement Schedule score of 45.21 and above)- Adjusted odds ratio 4.824, (95% CI 2.004 – 11.609) and p value <0.001. Being single might reflect the feeling of being less accomplished in life due to reduced chances of marriage and higher possibility of divorce and seperation as explained by Abu-Habib in her book on working with disabled women (113). Lloyds in her article on the politics of disability and

feminism observes that disability affects child birth and sexuality (112). This could explain the poor quality of life scores in social domain among the single people with physical disabilities. The environmental domain of quality of life is determined by physical safety and transport, financial sources and home environement (177). In our study, factors which were significantly associated with poor quality of life in environmental domain were unemployment status- Adjusted odds ratio 2.404, (95%CI 1.181 – 4.894) and p value 0.016, lower socio-eocnomic status Adjusted odds ratio 3.371, (95% CI 1.788 – 7.702) and p value <0.001 and more severe disability (Disability Assessement Schedule score of 45.21 and above)- Adjusted odds ratio3.607, (95% CI 1.622 – 8.023) and p value 0.002. Literature has not established difference between disability and work capacity but many people continue to remain unemployed.

Depression is one of the leading disabling conditions. In our study 59.9% of the people with physical disabilities had negative feelings very often or always. Negative feelings were present quite often for 32.5% of the people with physical disabilities. King in her study among stroke patients observed that 33% of them were depressed (192). In the qualitative part of our study, when people with disabilities were enquired about negative feelings, their responses were social discrimination, stigma and the realization that one cannot become normal again were causes of negative feelings.

Among the 300 persons with disability, 90.6% of them reported severe/complete difficulty in employment based on the ICF grading and 55.7% of them reported severe/complete difficulty in community life. The relation between the presence of impairment and unemployment is well known. Manual occupations involving physical exertion along with additional work such as travelling to the work place, most of which are inaccessible for people with disabilities are reasons why difficulty in employment is experienced in this population (90). Poor community participation was discussed in the

qualitative part of our study and participants opined that lower socio-economic status, inability to marry, transport problems and financial constraints were reasons for poor participation. Of the 300 persons with disability, 99% had to work at lower level or earn less money due to their health condition.

In our study, 34% of the people with physical disabilities were dissatisfied about their health. Presence of a co-morbidity was observed in 24% of the people with disabilities. Presence of a disability especially severe ones which could affect their activities of daily living and associated co-morbid conditions could have generated dissatisfaction about health in this population.

Among the 300 primary caregivers, 76% of them were females. The most common (53.7%) relation between disabled and their caregiver was parent/child. Similar pattern has been observed in a study done in United States where, most of the caregivers were females 66% and 36% of all the caregivers were people who took care of their parents (149).

Of the 300 primary caregivers interviewed, 27.4% had poor quality of life and 92.4% of them had negative feelings often. Poor mental health of the caregivers was also observed in a study done among caregivers of stroke patients (11). Poor quality of life among caregivers has also been observed by Lin et al in their study among caregivers of intellectually disabled persons (200). In another study done among caregivers of patients with parkinsons disease, poor quality of life was observed in the caregivers (201). In the qualitative part of our study all the caregivers expressed that they experience poor quality of life.

Among the caregivers, 26.7% were dissatisfied about their health. In the qualitative part of our study, caregivers expressed that even if they fall sick they would have to continue caregiving and other routine duties at home. This might have produced general

dissatisfaction about health. Cheffings, in the report on national strategy on carers reports that 50% of carers feel that their health is negatively affected by caregiving (150). The observed dissatisfaction about their health could have risen from the additional responsibility of caregiving. McCullagh in her study among caregivers of stroke patients observed that level of disability was not associated with caregiver burden (152). Women and younger caregivers were identified as risk groups for caregiver burn-out in a study done among caregivers of stroke by van den Heuvel et al (11). However, in our study being an elderly caregiver and caregiving for a person with severe disability were significantly associated with poor quality of life of caregivers in physical domain. Elderly caregivers being at risk for poor quality of life has been proven by Morley et al in their study on caregivers of patients with parkinsons disease (201).

In our study the mean score of physical domain of quality of life for the caregivers was 41.63 and psychological domain was 58.29. However, Lin et al in their study among caregivers of intellectually disabled children noted mean scores of WHO QOL-BREF in physical and psychological domain to be 13.71 ± 2.35 and 12.21 ± 2.55 (200). The seemingly better scores in our study could be attributed to the fact that our study included any disability and any relation between the person with disability and the caregiver.

In our study, lower socioeconomic status, caregiver being a parent or child, severe disability of the person who is receiving the care and caregiver being elderly were found to be significantly associated with lower scores in the psychological domain of quality of life of the caregivers. However, Cormec in her article on meeting the health needs of caregivers observed that caregivers coped better if they were taking care of their loved ones (10).

In our study, socio-economic status was observed to be significantly associated with psychological, social and environemental domain of quality of life of caregivers. In a

study done among caregivers of schizophrenics by Caqueo-Urizar et al, employment status of the caregiver and in turn economic status of the household were affected due to caregiving and this adversely affected the quality of life of caregivers (198). Another study done among caregivers of intellectually disabled children observed that family income is significantly correlated with quality of life scores of caregivers (200). In the qualitative part of our study caregivers expressed that disability in the person for whom they provide care is the main reason for them experiencing poor quality of life.

In our study the prevalence of overweight and obesity among the people with disabilities was 23.7% based on the WHO classification. In the United states, 24.9% of the people with disabilities were found to be obese. Marin in his study among nutritional status among people with Down's syndrome observed that 36.8% were overweight and 36.8% were obese (9). Bertoli et al also found 14% obesity and 40% overweight in their study. They observed that there is excessive consumption of simple carbohydrates in this population but insufficient intake of minerals and fibre (8). In our study also it was found that 73.7% of the persons with disability had poor protein consumption, described by nil or only one serving of milk product everyday. In our study, 11.4% of the people with disability were also observed to have a decline in food intake for the past one month.

There is paucity of literature on the nutritional assessment of persons with disabilities. Mini nutritional assessment (MNA) scale was chosen for the nutritional assessement in our study due to its simplicity and ease of administration in community based settings. Of all the persons with disability, 51.7% were found to be at risk for malnutrition and 8.3% were malnourished as per the MNA scale. This in inspite of a functioning public distribution system in Tamil Nadu. Presence of more than one disability and more severe disability were significantly associated with malnutrition and being at risk for

malnutrition. To our knowledge, this is the first study to identify association between disability and malnutrition using the mini mutritional assessment scale.

In our study, women were observed to experience more severe disability as compared to males- Adjusted OR 2.275,(95% CI 1.295 – 3.996) and p value 0.004. Less access to training, lack of education, poor social and economic freedom could contribute to this finding (111,113).

The relation between poverty and disability has been studied extensively. Poverty causes disability and disability results in poverty (92). This has been observed in our study where poor socioeconomic status was significantly associated with severity of disability - Adjusted OR 1.940, (95% CI 1.049 - 3.588) and p value 0.035. In our study, severity of disability was more among the people with mental disabilities, as compared to the people with physical disabilities - Adjusted OR 9.013, (95% CI 3.956 – 20.538) and p value <0.001. This can be understood since people with mental disabilities experience twice the disability as compared to people with physical disabilities. Apart from the disability as such which affects their cognition and self care, stigma and false beliefs from the society robs them of job and education opportunities and community participation (175).

7. LIMITATIONS

1. Given the problems faced by the study population, it is possible that there was an expectation of some benefit from this study which in turn could have influenced their responses.
2. It was not always possible to separate the caregiver from the person with disability while administering the quality of life questionnaire. This could have modified some of their responses.
3. Quality of life of people with mental disabilities could not be measured as it was not possible to administer the questionnaire to them.

8. SUMMARY and CONCLUSIONS

Disability impacts the physical, psychological and social aspects of life. In our study we examined the quality of life of people with disability and their primary caregivers. Studies on quality of life and disability have been done in developed countries but scarce in developing countries like India. We studied 300 persons with disabilities and 300 of their primary caregivers. Based on the findings from the quantitative and qualitative part of our study we conclude that the people with disabilities and their primary caregivers experience poor quality of life. Apart from the cause and severity of disability, factors such as socio-economic, employment and marital status were significantly associated with poor quality of life among the people with disabilities. Our study observed that people with acquired disabilities have a poorer quality of life than people born with disabilities. We can conclude that economic deprivation has significant impact on the quality of life of people with disabilities. While little can be done about the disability and its severity, economic indepedence is a meaningful intervention which can play a key role in improving the quality of life of people with disabilities.

While the people with disabilites had near equal gender distribution (males 52% and females 48%), more than 75.% of the primary caregivers were females. Caregiving roles were usually taken up by the female in the family. This finding was confirmed again in the qualitative part of the study. Marriage is considered as a form of social security in Indian culture. In our study 63.3% of the people with disabilities were single and most of them were illiterate, unemployed and poor at the time of interview. More than half the persons with disabilities had severe and complete difficulties in community participation. In the qualitative part of our study, we observed that the prospect of a person with disability getting married is fraught with difficulties, due to the cultural beliefs about disability, discrimination at work places and barriers experienced in education and

occupation. In our study more than half of the people with disability were found to be at risk for malnutrition or malnourished. Nutritional aspects of people with disability are not sufficiently addressed in the present health care programmes and this area needs to be studied further. Severe disability and presence of more than one disability were found to be significantly associated with malnutritiona and with being at risk for malnutrition in the regression model.

The study showed that among the primary caregivers, more than half reported getting negative feelings quite often and 27.4% reported poor quality of life. Burden due to caregiving which can cause stress, burn out and depression was not assessed in this study but findings suggest a significant proportion experiencing depression possibly due to the role of caregiving. Similar to quality of life of persons wih disabilities, poor socio-economic status was associated with poor quality of life among the primary caregivers. In our qualitative study it was revealed that discrimination and stigma was equally shared by caregivers also. With the disability affecting all aspects of life for the person experiencing it, it also impacts the caregiver and other family members due its profound economic, social and physical effects. The study examined some of the important aspects of a person with disability such as quality of life, caregiver quality of life, nutritional status, severity of disability and functional assesment. In the coming years, there will be an increase in the number of persons with disability owing to the advancing health care in the community. However disability affects quality of life adversly, not solely by itself but due to external factors such as the society, environment and the culture. Attending to the economic, social and employment needs of a person with disability could possibly alleviate the negative aspects of disability. Caregiver health and quality of life is less studied and explored in our country.

9. RECOMMENDATIONS

Our study findings and literature review finds that, there is very little research done in the field of disability, quality of life and caregiver health in the developing countries especially India. Available literature is by and large done in developed nations whose rehabilitative services and social security schemes are not comparable with the developing world. We recommend further studies on the quality of life, disability and caregiving.

Policies and legislations on improvement of autonomy, economic freedom and dwellings, public places devoid of barriers should be advocated.

Community based rehabilitation services which promises social inclusion and community participation could potentially improve the quality of life of the people with disabilities.

Community education on acceptance of persons with disability into the community and understanding the needs and difficulties faced by the person with disability

Caregiver training and support, which is an unexplored area in developing nations can be initiated to attended to the health and mental needs of this population.

Nutritional assessment and management of malnutrition is of concern among the people with disabilities. There is a need for creating awareness among health professionals regarding this issue.

Stringent legislations on bribery in disability related schemes such as pensions and employment opportunities should be imposed.

Training of persons with disabilities on skills that would help them start on a gainful employment.

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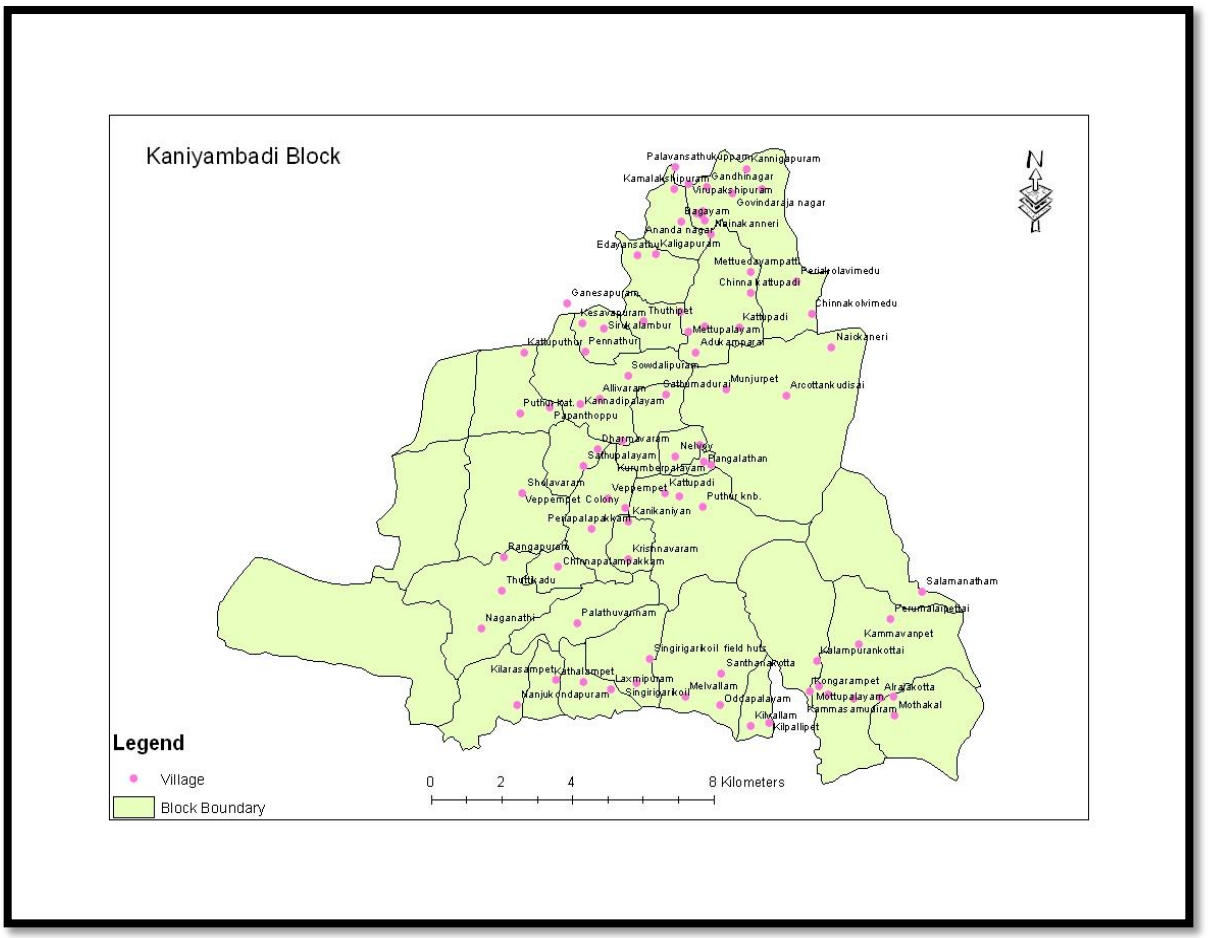
11. ANNEXURES

ANNEXURE 1: Map of the Kaniyambadi block



ANNEXURE 2

Questionnaire Part 1.

1. Name
2. Sex
3. Age
4. Date of birth / year of birth
5. Marital status : i) unmarried ii) married iv) separated v) widowed vi) divorced
6. Identity number :
7. Head of the house
8. House number
9. Street name
10. Village name
11. Literacy: i) Illiterate ii) read iii) read and write
12. Education: i) nil ii) primary school iii) middle school iv) high school v) higher secondary vi) intermediate or post high school diploma vii) graduate or post graduate viii) profession or honours
13. Occupation : i) Unemployed ii) Unskilled worker iii) Semi-skilled worker iv) Skilled worker, Clerical, Shop-owner, Farmer vi) Semi-Profession vii) Profession
14. Monthly family income in rupees: i) $\leq$ 1600 ii) 1601 – 4809 iii) 4810 – 8009 iv) 8010 – 12019 v) 12020 – 16019 vi) 16020 – 32049 v) $\geq$32050
15. Socio economic class: i) lower ii) upper lower iii) middle / lower middle iv) upper middle v) upper
16. Type of house : i) hut ii) kutcha iii) mixed house iv) Pucca house v) mansion
17. Family type : i) nuclear family ii) extended family iii) joint family
18. Religion : i) Hindu ii) Christian iii) Muslim
19. Functional status : i) normal ii) visual iii) hearing / speaking iv) motor v) sensory vi) emotional disturbance vii) fits viii) developmental delay ix) learning problems x) breathing xi) others

20. What is the cause of disability?

21. Other chronic illness :

22. Duration of disability :

23. On regular medications : i) yes ii) no

24. Use of any aids for disability :

25. Receiving disability pension: i) yes ii) no

26. Any substance abuse :i) yes ii) no

27. If yes name the substance :

28. Relationship of the disabled to the caregiver and vice versa:

29. Duration of care giving:

ANNEXURE 3

INTERNATIONAL CLASSIFICATION OF FUNCTIONING, DISABILITY AND HEALTH: FUNCTIONAL STATUS ASSESSMENT

S. No	Activity	Qualifiers (0-4)
	SELF CARE	
1.	Eating	
2.	Drinking	
3.	Caring for body parts	
4.	Washing oneself	
5.	Dressing	
6.	Toileting	
	COMMUNICATION	
8.	Understands spoken messages	
9.	Understands non-verbal messages	
10.	Speaking	
11.	Producing non-verbal messages	
	FUNCTIONAL ABILITY AND MOBILITY	
12.	Sitting	
13.	Standing	
14.	Walking	
15.	Moving around within the home	
16.	Moving around outside the home and other buildings	

MENTAL FUNCTIONS		
17.	Orientation functions	
18.	Intellectual functions	
SENSORY FUNCTIONS		
19.	Vision	
20.	Hearing	

S. No	Activity	Qualifiers (0-4)
COMMON ROLES IN THE HOME AND COMMUNITY		
21.	Recreation and leisure	
22.	Schooling	
23.	Employment	
24.	Doing housework	
25.	Community life	

QUALIFIER	DESCRIPTION	PERCENTAGE
0	No difficulty (none, absent, negligible)	0 – 4 %
1	Mild difficulty (slight, low)	5 – 24 %
2	Moderate difficuty (medium, fair)	25 – 49 %
3	Severe difficulty (high, extreme)	50 – 95%
4	Complete difficulty (total)	96 – 100 %
9	Not applicable	

ANNEXURE 4

WHO DISABILITY ASSESSMENT SCHEDULE (DAS) 2.0

Domain 1 : Cognition

In the past 30 days, how much difficulty did you have in		None	Mild	Moderate	Severe	Extreme Cannot do
D1.1	Concentrating on doing something for ten minutes	1	2	3	4	5
D1.2	Remembering to do important things	1	2	3	4	5
D1.3	Analysing and finding solutions to problems in day-to-day life	1	2	3	4	5
D1.4	Learning a new task	1	2	3	4	5
D1.5	Generally understanding what peeople say	1	2	3	4	5
D1.6	Starting and maintaining a conversation	1	2	3	4	5

Domain 2: Mobility

In the past 30 days, how much difficulty did you have in		None	Mild	Moderate	Severe	Extreme Cannot do
D2.1	Standing for long periods such as 30 minutes	1	2	3	4	5
D2.2	Standing up from sitting down	1	2	3	4	5
D2.3	Moving around inside your home	1	2	3	4	5
D2.4	Getting out of your home	1	2	3	4	5
D2.5	Walking a long distance such as kilometer	1	2	3	4	5

Domain 3: Self-care

In the past 30 days, how much difficulty did you have in		None	Mild	Moderate	Severe	Extreme Cannot do
D3.1	Washing your whole body	1	2	3	4	5
D3.2	Getting dressed	1	2	3	4	5
D3.3	Eating	1	2	3	4	5
D3.4	Staying by yourself for a few days	1	2	3	4	5

Domain 4: Getting along with people

In the past 30 days, how much difficulty did you have in		None	Mild	Moderate	Severe	Extreme Cannot do
D4.1	Dealing with people you do not know	1	2	3	4	5
D4.2	Maintaining friendship	1	2	3	4	5
D4.3	Getting along with people who are close to you	1	2	3	4	5
D4.4	Making new friends	1	2	3	4	5
D4.5	Sexual activities	1	2	3	4	5

Domain 5: Life activities . 5(1) Household activities

In the past 30 days, how much difficulty did you have in		None	Mild	Moderate	Severe	Extreme Cannot do
D5.1	Taking care of your household responsibilities	1	2	3	4	5
D5.2	Does your most important household tasks well	1	2	3	4	5
D5.3	Getting all the household work done that you needed to do	1	2	3	4	5
D5.4	Getting your household works done as quickly as possible	1	2	3	4	5

If any of the responses to D5.2 - D5.5 are rated greater than none (coded as "1"), as:

D5.01	In the past 30 days, on how many days did you reduce or completely miss household work because of your health condition?	**Record number of days**

5(2) Work or school activities

In the past 30 days, how much difficulty did you have in		**None**	**Mild**	**Moderate**	**Severe**	**Extreme Cannot do**
D5.1	Your day-to-day work/school	1	2	3	4	5
D5.2	Doing your most important work/school tasks well	1	2	3	4	5
D5.3	Getting all the work done that you need to do	1	2	3	4	5
D5.4	Getting your work done as quickly as needed	1	2	3	4	5
D5.5	Have you had to work at a lower level because of a health condition				No	1
					Yes	2
D5.6	Did you earn less money as the result of a health condition				No	1
					Yes	2

If any of D5.5 – D5.8 are rated greater than none (coded as "1"), ask:

D5.02	In the past 30 days, on how many days did you miss work for half a day or more because of your health condition	**Record number of days**

Domain 6: Participation

In the past 30 days, how much difficulty did you have in		None	Mild	Moderate	Severe	Extreme Cannot do
D6.1	How much of a problem did you have joining in community activities	1	2	3	4	5
D6.2	How much of a problem did you have because of barriers or hindrances in the world around you	1	2	3	4	5
D6.3	How much of a problem did you have living with diginity because of the sttitudes and actions of others	1	2	3	4	5
D6.4	How much time did you spend on your health condition or its consequences	1	2	3	4	5
D6.5	How much have you been emotionally affected by your health condition	1	2	3	4	5
D6.6	How much has your health been a drain on the financial resources of you or your family	1	2	3	4	5
D6.7	How much of a problem did your family have because of your health condition	1	2	3	4	5
D6.8	How much of a problem did you have in doing things by yourself for relaxation or pleasure	1	2	3	4	5

H1	Overall in the past 30 days, how many days were these difficulties present	
H2	In the past 30 days, for how many days were you totally unable to carry out your usual activities or work because of any health condition	
H3	In the past 30 days, not counting the days you were totally unable, for how many days did you cut back or reduce your usual activities or work because of health condition	

ANNEXURE 5

MINI NUTRITIONAL ASSESSMENT (MNA)

Height:

Weight:

If bedridden, abdominal circumference:

Demi-arm span:

Knee Height:

SCREENING:

a) **Has food intake declined over the past 3 months due to loss of appetite, digestive problems, chewing or swallowing difficulties?**
   0 = severe decrease in food intake
   1 = moderate decrease in food intake
   2 = no decrease in food intake
b) **Weight loss during the last 3 months**
   0 = weight loss greater than 3 kg
   1 = does not know
   2 = weight loss between 1 and 3 kg
   3 = no weight loss
c) **Mobility**
   0 = bed or chair bound
   1 = able to get out of bed / chair but does not go out
   2 = goes out
d) **Has suffered psychological stress or acute disease in the past 3 months?**
   0 = yes
   1 = no
e) **Neuropsychological problems**
   0 = severe dementia
   1 = mild dementia
   2 = no psychological problems

f) Body Mass Index (BMI) (Weight in Kg / (Height in mt)^2)

0 = BMI less than 19

1 = BMI 19 to less than 21

2 = BMI 21 to less than 23

3 = BMI 23 or greater

ASSESSMENT

g) Lives independently (not in nursing home or hospital)

1 = yes

0 = no

h) Takes more than 3 prescription drugs per day

0 = yes

1 = no

i) How many full meals does the patient eat daily?

0 = 1 meal

1 = 2 meals

2 = 3 meals

j) Selected consumption markers for protein intake

. At least one serving of dairy products (milk, cheese yoghurt) per day yes/ no

. Two or more servings of legumes or eggs per week yes/ no

. Meat, fish or poultry every day yes/ no

0.0 = if 0 or 1 yes

0.5 = if 2 yes

1.0 = if 3 yes

k) Consumes two or more servings of fruit or vegetables per day?

0 = no

1 = yes

l) How much fluid (water, juice, coffee, tea, milk…) is consumed per day?

0.0 = less than 3 cups

0.5 = 3 to 5 cups

1.0 = more than 5 cups

m) Mode of feeding

0 = unable to eat without assistance

1 = self-fed with some difficulty

2 = self-fed without any problem

n) Self view of nutritional status

0 = views self as being malnourished

1 = is uncertain of nutritional state

2 = views self as having no nutritional problem

o) In comparison with other people of the same age, how does the patient consider his / her health status?

0.0 = not as good

0.5 = does not know

1.0 = as good

2.0 = better

p) Mid-arm circumference (MAC) in cm

0.0 = MAC less than 21

0.5 = MAC 21 to 22

1.0 = MAC 22 or greater

q) Calf circumference (CC) in cm

0 = CC less than 31

1 = CC 31 or greater

ANNEXURE 6

WHO QOL-BREF

1. **How would you rate your quality of life?**

Very poor	poor	Neither poor nor good	Good	Very good
1	2	3	4	5

2. **How satisfied are you with your health**

Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
1	2	3	4	5

3. **To what extent do you feel that physical pain prevents you from doing what you need to do**

Not at all	A little	A moderate amount	Very much	An extreme amount
5	4	3	2	1

4. **How much do you need any medical treatment to function in your daily life?**

Not at all	A little	A moderate amount	Very much	An extreme amount
5	4	3	2	1

5. **How much do you enjoy life?**

Not at all	A little	A moderate amount	Very much	An extreme amount
1	2	3	4	5

6. To what extent do you feel your life to be meaningful?

Not at all	A little	A moderate amount	Very much	An extreme amount
1	2	3	4	5

7. How well are you able to concentrate

Not at all	A little	A moderate amount	Very much	An extreme amount
1	2	3	4	5

8. How safe do you feel in your daily life?

Not at all	A little	A moderate amount	Very much	An extreme amount
1	2	3	4	5

9. How healthy is your physical environment?

Not at all	A little	A moderate amount	Very much	An extreme amount
1	2	3	4	5

10. Do you have enough energy for everyday life?

Not at all	A little	A moderate amount	Very much	An extreme amount
1	2	3	4	5

11. Are you able to accept your bodily appearance

Not at all	A little	A moderate amount	Very much	An extreme amount
1	2	3	4	5

12. Have you enough money to meet your needs?

Not at all	A little	A moderate amount	Very much	An extreme amount
1	2	3	4	5

13. How available to you is the information that you need in your day-to-day life?

Not at all	A little	A moderate amount	Very much	An extreme amount
1	2	3	4	5

14. To what extent do you have the opportunity for leisure activities?

Not at all	A little	A moderate amount	Very much	An extreme amount
1	2	3	4	5

15. How well are you able to get around?

Very poor	poor	Neither poor nor good	Good	Very good
1	2	3	4	5

16. How satisfied are you with your sleep?

Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
1	2	3	4	5

17. How satisfied are you with your ability to perform your daily living activities?

Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
1	2	3	4	5

18. How satisfied are you with your capacity for work?

Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
1	2	3	4	5

19. How satisfied are you with yourself?

Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
1	2	3	4	5

20. How satisfied are you with your personal relationships?

Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
1	2	3	4	5

21. How satisfied are you with your sex life?

Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
1	2	3	4	5

22. How satisfied are you with the support you get from your friends?

Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
1	2	3	4	5

23. How satisfied are you with the conditions of your living place?

Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
1	2	3	4	5

24. How satisfied are you with your access to health services?

Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
1	2	3	4	5

25. How satisfied are you with your transport?

Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
1	2	3	4	5

26. How often do you have negative feelings such as blue mood, despair, anxiety and depression?

Never	Seldom	Quite often	Very often	Always
5	4	3	2	1

ANNEXURE 7

INFORMATION SHEET IN ENGLISH:

A study of the severity of disability and nutritional status of the disabled, quality of life of the physically disabled and quality of life among the primary caregivers of disabled in Kaniyambadi block.

Informed consent document: This informed consent information sheet applies to adult consent (over 18 years old)**.** The following information is provided to inform you about the research project and your participation in it. Please read this form carefully and feel free to ask any questions you may have about this study and information given below. You will be given an opportunity to ask questions, and your questions will be answered. Also, you will be given a copy of this information sheet. Your participation in this research study is voluntary. You are also free to withdraw from this at any time.

Purpose of the study: To assess the severity of disability and nutritional status among the disabled aged 18 years and above in Kaniyambadi block. To assess the quality of life of physically disabled and quality of life among primary care givers of the disabled in Kaniyambadi block.

Procedures to be followed and approximate duration of study: The study involves answering questions about your socio demographic details, disability status, quality of life and nutritional status. The investigator will come and perform the following procedures:

1. **The investigator will assess your disability by asking questions, if you are disabled. If you are a caregiver with no disability, then this part will be skipped.**

2. **Following this, will be questions about your socio demographic details and quality of life**
3. **Questions will be asked about the nutritional status also.**

Approximate duration of study: October 2013 to September 2014.

Expected cost: Nil

Description of the discomforts, inconveniences, and / or risks that that can be reasonably expected as a result of participation in this study: There are no major risks associated with this procedure.

Unforeseeable risk: Nil

Compensation in case of study-related injury: Nil

Anticipated benefits from this study: While persons with disabilities make up ten per cent of the world's population, disability is associated with twenty per cent of global poverty according to the World Bank's findings. Disabling conditions have always separated those who have them from the mainstream experience of culture and society. People living with functional impairments are often excluded from education and employment leading to an increased risk of poverty. They often face restrictions to their inclusion and participation in society, including reduced access to education and health care. This study aims for deeper understanding of the severity of disability and nutritional status of the disabled and quality of life of their primary caregivers. The results of the study can help in the betterment of the quality of life of physically disabled and the primary caregivers of disabled and can be used for policy making and decision making for programs for the disabled.

Alternative treatment available: Not applicable. **Compensation for participation:** Nil

Circumstances under which the principal investigator may withdraw you from the study participation: nil

What happens if you choose to withdraw from study participation? Your data will not be included in any result.

Contact information: If you have any questions about this research study or possibly, please feel free to contact: Dr.G Nancy Angeline 9942221783 or Dr.Vinod Joseph Abraham 9443253772. Also feel free to find more information about the Christian Medical College's Institutional Review Board at 0416-2284207.

Confidentiality: All efforts, within reason, will be made to keep your personal information in your research record confidential. When the results of this study is being discussed, your name will not be used or published.

Privacy: Your information may be shared with, the Christian Medical College, or the government, Christian Medical College Institution Review Board, if we required to do so by law.

ANNEXURE 8

INFORMED CONSENT FORM IN TAMIL:

மாற்றுத்திறனாளிகளின் குறைபாட்டின் தீவிரம், ஊட்டச்சத்து நிலை, உடல் ஊனமுற்றவர்களின் வாழ்க்கைத்தரம் மற்றும் மாற்றுத்திறனாளிகளின் முதன்மை பராமரிப்பாளர்களின் வாழ்க்கைத்தரம் பற்றிய ஆராய்ச்சி.

தகவல் படிவம்

இந்தத் தகவல் மற்றும் ஒப்புதல் படிவம் 18 வயதிற்கு மேற்ப்பபட்டவற்கு மட்டுமே பொருந்தும். இந்தத் தகவல் மற்றும் ஒப்புதல் படிவமானது மேற்கூறப்பட்ட ஆராய்ச்சித் திட்டம் பற்றியும் அதில் உங்களது பங்களிப்பையும் பற்றியது. இந்த படிவத்தை கவனமாக வாசிக்கவும். இந்த ஆராய்ச்சி பற்றியோ கீழ் கூறப்பட்ட தகவலைப்பற்றியோ எந்தவிதமான கேள்விகள் இருந்தாலும் கேட்கத் தயக்கப்பட வேண்டாம். உங்களுக்கு கேள்விகள் கேட்பதற்கு வாய்ப்பளிக்கப்படும் மற்றும் உங்கள் கேள்விகளுக்கு பதிலும் அளிக்கப்படும். இந்தத் தகவல் படிவத்தின் நகல் உங்களுக்கு கொடுக்கப்படும். இந்த ஆராய்ச்சியில் உங்களது பங்களிப்பு முற்றிலும் தனிச்சையானது. இந்த ஆராய்ச்சியிலிருந்து எந்த நேரமும் விலகிக் கொள்ளலாம்.

இந்த ஆராய்ச்சியின் நோக்கம்: மாற்றுத்திறனாளிகளின் குறைபாட்டின் தீவிரம், ஊட்டச்சத்து நிலை மற்றும் உடல் ஊனமுற்றவர்களின் வாழ்க்கைத்தரம் மற்றும் மாற்றுத்திறனாளிகளின் முதன்மை பராமரிப்பாளர்களின் வாழ்க்கைத்தரத்தை மதிப்பிடுவதே இந்த ஆராய்ச்சியின் நோக்கம். இந்த ஆராய்ச்சியின் மூலம் மாற்றுத்திறனாளிகள் மற்றும் அவர்களின் முதன்மை பராமரிப்பாளர்களின் வாழ்க்கைத்தரம் பற்றி அதிகமான புரிதல் ஏற்படும் என எதிர்பார்க்கப்படுகிறது. அதன் மூலம் கிடைக்கும் முடிவுகள், மாற்றுத்திறனாளிகள் மற்றும் அவர்கள் குடும்பங்களின் வாழ்க்கைத்தரத்தை மாற்றத்தக்க கொள்கைகள் மற்றும் திட்டங்களை வடிவமைப்பதற்கு உதவி புரியும் என எதிர்ப்பார்க்கப்படுகிறது.

பின்பற்ற வேண்டிய திட்டமுறைகள் மற்றும் ஆராய்ச்சியின் காலவரை: இந்த ஆராய்ச்சியில், உங்கள் சமூக பொருளாதாரம், குறைபாட்டின் தீவிரம், வாழ்க்கைத்தரம், ஊட்டச்சத்து நிலை ஆகியவற்றைப் பற்றி சில கேள்விகளுக்கு பதிலளித்தலும், அடங்கும். **ஆராய்ச்சியின் காலவரை:** அக்டோபர் 2013 முதல் செப்டம்பர் 2014 வரை

ஆராய்ச்சியாளர் உங்களிடம் வந்து கீழ்க்காணும் திட்டமுறைகளை செய்வார்:

1. உங்களின் மாற்றுத்திறன் நிலை குறித்து சில கேள்விகள் கேட்கப்பட்டு ஆராய்ச்சியாளரால் பரிசோதிக்கப்படும். நீங்கள் ஒரு முதன்மை பராமரிப்பாளராயிருந்து உங்களுக்கு மாற்றுத்திறன் நிலை இல்லையெனில் இக்கேள்விகள் கேட்கப்படாது.
2. இதற்குப்பின் உங்களின் சமூக பொருளாதார நிலை பற்றிக் கேள்விகள் கேட்கப்படும்.
3. நீங்கள் உடல் ஊனமுற்றவ்ராயிருந்து, மாற்றுத்திறனாளிகளின் முதன்மை பராமரிப்பாளராயிருந்தால் வாழ்க்கைத்தரத்தை பற்றி கேள்விகள் கேட்கப்படும்
4. உங்கள் ஊட்டச்சத்து நிலைப் பற்றி கேள்விகள் கேட்கப்படும்.

ஆராய்ச்சியின் காலவரை : 12மாதம் அக்டோபர் 2013 முதல் செப்டம்பர் 2014 வரை.

எதிர்ப்பார்க்கப்படும் செலவு : எதுவும் இல்லை.

இந்த ஆராய்ச்சியில் பங்குபெறுவதால் எதிர்ப்பார்க்கப்படும் அசௌகரியங்கள்:

இந்த ஆராய்ச்சியில் பங்குபெறுவதால் எந்த பெரிய பாதிப்பும் ஏற்படுவதில்லை.

எதிர்பாராமல் நிகழும் ஆபத்து: எதுவும் இல்லை.**ஆராய்ச்சியினால் காயம் ஏற்பட்டால் கொடுக்கப்படும் ஈடு** : எதுவும் இல்லை

இந்த ஆராய்ச்சியால் எதிர்ப்பார்க்கப்படும் நன்மைகள்: உலக மக்கள் தொகையில் பத்து சதவீதம் பேர் மாற்றுத்திறனாளிகள் தான். உலக ஏழ்மையில் இருபது சதவீதம் மாற்று திறமையால் ஏற்படக்கூடிய ஏழ்மைக்கு தொடர்புள்ளது என உலகவங்கி கண்டுபிடித்துள்ளது. ஊனமுற்ற நிலைமை மனிதர்களை முக்கியமாக கலாச்சாராங்களிலிருந்தும் சமூகத்திலிருந்தும் பிரித்தெடுக்கிறது. மாற்றுத்திறனாளிகளுக்கு கல்வியும், வேலைவாய்ப்பும் மறுக்கப்படுவதால், அவர்கள் மேலும் ஏழ்மைக்கு தள்ளப்படுகிறார்கள். அவர்கள் சமூகத்தில் பங்களிப்பது, கல்வி, மருத்துவ உதவி ஆகியவற்றில் தடைகளைக் காண்கிறார்கள். இந்த ஆராய்ச்சியின் மூலம் மாற்றத்திறனாளிகள் மற்றும் அவர்களின் முதன்மை பராமரிப்பாளர்களின் வாழ்க்கைத்தரம் ,ஊட்டச்சத்து நிலை இவற்றைப் பற்றி தெளிவான விரிவான புரிதல் ஏற்படும். இந்த ஆராய்ச்சியின் முடிவுகள் மாற்றுத்திறனாளிகள் மற்றும் அவர்களின் முதன்மை பராமரிப்பாளர்களின் வாழ்க்கைத்தரம் மேம்பட உதவிபுரியும் எனவும், வருங்காலத்தில் மாற்றுத்திறனாளிகளுக்கான கொள்கைகள், திட்டங்கள் உருவாகுவதற்கு உதவிபுரியும் என நம்பப்படுகிறது.

மாற்று முறை சிகிச்சை கிடைக்குமா? : இல்லை.

நீங்கள் ஆராய்ச்சியில் பங்குபெற முடியாதபடி ஆராய்ச்சியாளர் உங்களை ஆராய்ச்சியிலிருந்து விலக்கும் சந்தர்ப்பங்கள்

: எதுவும் இல்லை.

நீங்கள் ஆராய்ச்சியிலிருந்து விலக நினைத்தால் என்ன நடக்கும்: உங்கள் கேள்வித்தாள் அழிக்கப்பட்டு, உங்கள் பதில்கள் ஆராய்ச்சியின் முடிவில் சேர்க்கப்படாது.

தொடர்புக்கு: இந்த ஆராய்ச்சியைப் பற்றி உங்களுக்கு எந்த கேள்விகள் இருந்தாலும் கீழ்க்காணும் நபர்களை தொடர்புகொள்ள தயக்கப்பட வேண்டாம். **மரு. நான்சி ஏஞ்சலின் 9942221783. மரு. வினோத் ஜோசப் ஆபிரஹாம் 9443253772. கிறிஸ்தவ மருத்துவக் கல்லூரியின் நிறுவன ஆய்வுக்குழு 0416 – 2284207 இல்** எந்த தகவலுக்காகவும் தொடர்புகொள்ள தயக்கப்பட வேண்டாம்.

நம்பகத்தன்மை: ஆராய்ச்சிப்படிவத்தில் நீங்கள் கொடுத்த தனிப்பட்ட தகவல்கள் இரகசியமாக பாதுகாக்கப்பட எல்லா முயற்சிகளும் எடுக்கப்படும். இந்த ஆராய்ச்சியின் முடிவுகள் விவாதிக்கப்படும்போது உங்கள் பெயர் பயன்படுத்தப்பட மாட்டாது.

இரகசியத்தன்மை: தேவைப்படும் போது சட்டத்திற்கு உட்பட்ட உங்கள் தகவல்கள் **கிறிஸ்தவ மருத்துவக் கல்லூரி, அரசு அல்லது நிறுவன ஆய்வு குழுவிடம்** பகிரப்படலாம்

ANNEXURE 9

INFORMED CONSENT DOCUMENT IN ENGLISH

Study Title: A study of the severity of disability and nutritional status of the disabled, quality of life of the physically disabled and quality of life among the primary caregivers of disabled in Kaniyambadi block.

Subject's name----------

Date of birth/Age----------

Before you agree, the investigator must tell you about

(i) the purposes, procedures and duration of research;

(ii) the procedures which are experimental;

(iii) any foreseeable risks, discomforts and benefits of the research;

(iv) how confidentiality will be maintained.

(v) The investigator must also tell you about (i) any available compensation or medical treatment if injury occurs;(ii) the possibility of unforeseeable risks; (iii) circumstances when the investigator may halt your participation;(iv) any added costs to you; (v) what happens if you decide to stop participating.

If you agree to participate, you must be given a signed copy of this document and a written summary of the research.

Please initial the box:

(i) I confirm that I have read and understood the information sheet/ it has been read to me and I understand the information sheet dated----------for the above study and have had the opportunity to ask questions ( ).

(ii) I understand that my participation in the study is voluntary and that I am free to withdraw at any time, without giving any reason without my medical care and legal rights being affected ( ).

(iii) I understand that Sponsor of the study, others working on the sponsor's behalf, the Ethics committee and regulatory authorities will not need my permission to look at my health records both in respect of the current study and any further research that may be conducted in relation to it, even if I withdraw from the trial. I agree to this access. However, I understand that my identity will not be revealed in any information released to third parties or published ( ).

(iv) I agree not to restrict the use of any data or results that arise from this study provided such a use is only for scientific purpose(s) ( ).

(v) I agree to participate in the above study ( ).

If you have any questions about this research study, please contact Dr. Nancy Angeline at 9942221783 or my guide Dr. Vinod Joseph Abraham at 9443253772. Your participation in this research is voluntary, and you will not be penalized or lose benefits if you refuse to participate or decide to stop.

Signing this document means that the research study, including the above information, has been described to you orally, and that you voluntary agree to participate.

Signature of the participant …….....

Date……

Signature of the Witness …….

Date……

ANNEXURE 10

INFORMED CONSENT FROM IN TAMIL

தகவலறிந்த ஒப்புதல் படிவம்

ஆராய்ச்சித் தலைப்பு: **மாற்றுத்திறனாளிகளின் குறைபாட்டின் தீவிரம், ஊட்டச்சத்து நிலை, உடல் ஊனமுற்றவர்களின் வாழ்க்கைத்தரம் மற்றும் மாற்றுத்திறனாளிகளின் முதன்மை பராமரிப்பாளர்களின் வாழ்க்கைத்தரம் பற்றிய ஆராய்ச்சி.**

பங்கு பெறுபவரின் பெயர் :

பிறந்த வருடம் ∴ வயது :

இந்த ஆராய்ச்சியில் பங்குபெறும் முன்பு முதன்மை ஆராய்ச்சியாளர் உங்களிடம் கூறவேண்டுவன

1. ஆராய்ச்சியின் நோக்கம், செயல்முறைகள் மற்றும் நீடிக்கும் காலம்.
2. பரிசோதனை செயல்முறைகள்.
3. எதிர்பார்க்கப்படும் அபாயங்கள் , அசௌகரியங்கள் மற்றும் நன்மைகள்
4. நம்பகத்தன்மை எவ்வாறு தக்கவைக்கப்படுகிறது.

உங்களிடம் முதன்மை ஆராய்ச்சியாளர் இதையும் கூற வேண்டும்.

1. காயம் ஏற்பட்டால் கிடைக்கக்கூடிய ஈடு அல்லது மருத்துவ சிகிச்சை.
2. எதிர்பாராத அசௌகரியங்கள் நடக்கும் வாய்ப்பு.
3. நீங்கள் ஆராய்ச்சியில் பங்கு பெறுவதை முதன்மை ஆராய்ச்சியாளர் தடை செய்யும் தருணங்கள்.
4. உங்களுக்கு ஏற்படும் கூடுதல் செலவு.
5. நீங்கள் ஆராய்ச்சியில் பங்கு பெறுவதை நிறுத்த நினைத்தால் என்ன நடக்கும்.
   இந்த ஆராய்ச்சியில் பங்குபெற நீங்கள் சம்மதித்தால், கையெழுத்திட்ட அந்த படிவமும்,
   எழுதப்பட்ட ஆராய்ச்சியின் சுருக்கமும் உங்களுக்குக் கொடுக்கப்பட வேண்டும்.

கொடுக்கப்பட்ட கட்டங்களில் தயவுசெய்து கையெழுத்திடவும்.

1. மேற்காணும் ஆராய்ச்சிக்கான, ¨¨¨¨¨¨¨¨¨¨¨¨ தேதியிட்ட தகவல் படிவத்தை நான் வாசித்தும் புரிந்தும் கொண்டேன்∴ எனக்கு வாசிக்கப்பட்டது என உறுதியளிக்கிறேன். எனக்கு கேள்வி கேட்பதற்கும் வாய்ப்பு கொடுக்கப்பட்டது
2. இந்த ஆராய்ச்சியில் நான் பங்கு பெறுவது முற்றிலும் தனிச்சையானது எனவும், எனது மருத்துவ சிகிச்சையோ, எனது சட்ட உரிமைகளோ பாதிக்கப்படாமலும்

எந்த காரணமும் இல்லாமலும் இந்த ஆராய்ச்சியிலிருந்து எப்பொழுது வேண்டுமானாலும் விலகிக் கொள்ள எனக்கு உரிமை இருக்கிறது.

3. இந்த ஆராய்ச்சிக்கான நிதியுதவி தருபவர், நிதியுதவி தருபவரின் சார்பில் பணி செய்பவர், நன்னடத்தை குழு மற்றும் ஒழுங்கு முறை அதிகாரிகள் என்னுடைய சுகாதார பதிவுகளை, இந்த நடப்பு ஆராய்ச்சியை பொறுத்தவரையோ, வருங்காலத்தில் இதன் தொடர்புள்ள ஆராய்ச்சிக்காகவோ, நான் இந்த ஆராய்ச்சியிலிருந்து விலகிக் கொண்டால் கூட, என் உத்தரவு இல்லாமல் கூட காணலாம் என புரிந்து கொண்டேன். இந்த அணுகுமுறைக்கு சம்மதம் தெரிவிக்கிறேன் ஆனால் என்னுடைய அடையாளம் எந்தவித தகவல்முறையிலும் ஒரு மூன்றாம் நபருக்கோ அல்லது பிரசுரிக்கப்பட்டு வெளிப்படுத்தப்படவோ மாட்டாது என புரிந்து கொள்கிறேன்.
4. இந்த ஆராய்ச்சியினால் வரும் தரவுகளையோ, முடிவுகளையோ அறிவியல்பூர்வமான காரியங்களுக்கு மட்டும் பயன்படுத்தும் பட்சத்தில், எவ்வித தடையும் செய்யமாட்டேன் என உறுதியளிக்கிறேன்.
5. இந்த ஆராய்ச்சியில் பங்குபெற உறுதியளிக்கிறேன்.

இந்த ஆராய்ச்சியைப் பற்றி எந்த விதமான கேள்விகள் இருந்தாலும் **மரு. நான்சி ஏஞ்சலின் 9942221783** அல்லது **மரு. வினோத் ஜோசப் ஆபிரஹாம் 9443253772 வில்** தொடர்பு கொள்ளவும். இந்த ஆராய்ச்சியில் உங்களது பங்குபெறுதல் முற்றிலும் தனிச்சையானது. இந்த ஆராய்ச்சியில் நீங்கள் பங்கு பெற மறுத்தாலோ அல்லது நிறுத்திக் கொள்ள முடிவு செய்தாலோ நீங்கள் தண்டிக்கப்படவோ அல்லது அனுகூலங்களை இழக்கவோ மாட்டீர்கள். இந்த பத்திரத்தில் கையெடுத்திடுவதின் மூலம், மேற்கூறப்பட்ட அனைத்து தகவல்களும், இந்த ஆராய்ச்சியும் உங்களுக்கு வாய்வழியாக விவரிக்கப்பட்டது எனவும், தனிச்சையாக இந்த ஆராய்ச்சியில் பங்குபெற சம்மதிக்கிறீர்கள் எனவும் புரிந்து கொள்ளப்படுகிறீர்கள்.

பங்குபெறுபவரின் கையெழுத்து: தேதி:

சாட்சியின் கையெழுத்து : தேதி:

ஆராய்ச்சியாளர் கையெழுத்து: தேதி:

ANNEXURE 11

IRB CLEARANCE

OFFICE OF RESEARCH
INSTITUTIONAL REVIEW BOARD (IRB)
CHRISTIAN MEDICAL COLLEGE, VELLORE, INDIA.

Dr. B.J. Prashantham, M.A., M.A., Dr. Min (Clinical)
Director, Christian Counseling Center,
Chairperson, Ethics Committee.

Dr. Alfred Job Daniel, D Ortho, MS Ortho, DNB Ortho
Chairperson, Research Committee & Principal

Dr. Nihal Thomas,
MD., MNAMS., DNB (Endo), FRACP (Endo), FRCP (Glas) (EDIN)
Deputy Chairperson
Secretary, Ethics Committee, IRB
Additional Vice Principal (Research)

October 08, 2013

Dr. Nancy Angeline. G
PG Registrar
Department of Community Health
Christian Medical College
Vellore 632 002

Sub: **Fluid Research grant project:**
A study of the severity of disability and nutritional status of the disabled, quality of life of the physically disabled and quality of life among the primary caregivers of disabled in Kaniyambadi block.
Dr. Nancy Angeline. G, PG Registrar, Community Health, Dr. Vinod Joseph Abraham, Community Health, Mr. Samuel Prasanna Vinothkumar. J, Community Health.

Ref: IRB Min. No. 8448 dated 10.09.2013

Dear Dr. Nancy Angeline. G,

I enclose the following documents:-

1. Institutional Review Board approval 2. Agreement

Could you please sign the agreement and send it to Dr. Nihal Thomas, Addl. Vice Principal (Research), so that the grant money can be released.

With best wishes,

Dr. Nihal Thomas
Secretary (Ethics Committee)
Institutional Review Board

Dr. NIHAL THOMAS
MD.,MNAMS.,DNB(Endo),FRACP(Endo),FRCP(Edin),FRCP(Glasg)
SECRETARY - (ETHICS COMMITTEE)
Institutional Review Board,
Christian Medical College, Vellore - 632 002.

CC: Dr. Vinod Joseph Abraham, Community Health, CMC.

OFFICE OF RESEARCH
INSTITUTIONAL REVIEW BOARD (IRB)
CHRISTIAN MEDICAL COLLEGE, VELLORE, INDIA.

Dr. B.J. Prashantham, M.A., M.A., Dr. Min (Clinical)
Director, Christian Counseling Center,
Chairperson, Ethics Committee.

Dr. Alfred Job Daniel, D Ortho, MS Ortho, DNB Ortho
Chairperson, Research Committee & Principal

Dr. Nihal Thomas,
MD., MNAMS., DNB (Endo), FRACP (Endo), FRCP (Glas) (EDIN)
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Secretary, Ethics Committee, IRB
Additional Vice Principal (Research)

October 08, 2013

Dr. Nancy Angeline. G
PG Registrar
Department of Community Health
Christian Medical College
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Sub: **Fluid Research grant project:**
A study of the severity of disability and nutritional status of the disabled, quality of life of the physically disabled and quality of life among the primary caregivers of disabled in Kaniyambadi block.
Dr. Nancy Angeline. G, PG Registrar, Community Health, Dr. Vinod Joseph Abraham, Community Health, Mr. Samuel Prasanna Vinothkumar. J, Community Health.

Ref: IRB Min. No. 8448 dated 10.09.2013

Dear Dr. Nancy Angeline. G,

The Institutional Review Board (Blue, Research and Ethics Committee) of the Christian Medical College, Vellore, reviewed and discussed your project entitled "A study of the severity of disability and nutritional status of the disabled, quality of life of the physically disabled and quality of life among the primary caregivers of disabled in Kaniyambadi block." on September 10, 2013.

The Committees reviewed the following documents:

1. Format for IRB application
2. CV's of Drs. Nancy Angeline .G, Vinod Joseph Abraham, Samuel Prasanna Vinothkumar.
3. Information Consent form in English & Tamil
4. The world health organization Quality of life (whoqol) –bref in English & Tamil
5. World health organization stability assessment schedule 2.0 in English & Tamil.

Dr. B.J. Prashantham, M.A., M.A., Dr. Min (Clinical)
Director, Christian Counseling Center,
Chairperson, Ethics Committee.

Dr. Alfred Job Daniel, D Ortho, MS Ortho, DNB Ortho
Chairperson, Research Committee & Principal

Dr. Nihal Thomas,
MD., MNAMS., DNB (Endo), FRACP (Endo), FRCP (Glas) (EDIN)
Deputy Chairperson
Secretary, Ethics Committee, IRB
Additional Vice Principal (Research)

6. Questionnaire for socio demographic status
7. Mini Nutritional Assessment in English & Tamil
8. No of documents 1-7

The following Institutional Review Board (Blue, Research & Ethics Committee) members were present at the meeting held on September 10, 2013 in the CREST/SACN Conference Room, Christian Medical College, Bagayam, Vellore 632002.

Name	Qualification	Designation	Other Affiliations
Dr. Benjamin Perakath	MBBS, MS, FRCS	Professor, Colorectal Surgery, CMCH.	Internal, Clinician
Dr. Anup Ramachandran	Ph. D	The Wellcome Trust Research Laboratory Gastrointestinal Sciences, CMCH.	Internal, Basic Medical Scientist
Dr. Mathew Joseph	MBBS, MCH	Professor, Neurosurgery, CMCH.	Internal, Clinician
Dr. Rajesh Kannangai	MD, Ph D.	Professor & In-charge Retrovirus Laboratory (NRL under NACO), Clinical Virology, CMCH.	Internal, Clinician
Dr. Paul Ravindran	PhD, Dip RP, FCCPM	Professor, Radiotherapy, CMCH.	Internal, Clinician
Dr. Susanne Abraham	MBBS, MD	Professor, Dermatology, Venerlogy & Leprosy, CMCH.	Internal, Clinician
Dr. Balamugesh	MBBS, MD(Int Med), FCCP (USA)	Professor, Pulmonary Medicine, CMCH.	Internal, Clinician
Dr. Anil Kuruvilla	MBBS, MD, DCH	Professor, Child Health, CMCH.	Internal, Clinician
Dr. Simon Rajaratnam	MBBS, MD, DNB (Endo), MNAMS (Endo), PhD (Endo), FRACP	Professor, Endocrinology, CMCH.	Internal, Clinician

Ethics Committee Blue, Office of Research, 1st Floor, Carman Block, Christian Medical College, Vellore, Tamil Nadu 632 002.
Tel : 0416 - 2284294, 2284202 Fax : 0416 - 2262788, 2284481 E-mail : research@cmcvellore.ac.in

Dr. B.J. Prashantham, M.A., M.A., Dr. Min (Clinical)
Director, Christian Counseling Center,
Chairperson, Ethics Committee.

Dr. Alfred Job Daniel, D Ortho, MS Ortho, DNB Ortho
Chairperson, Research Committee & Principal

Dr. Nihal Thomas,
MD., MNAMS., DNB (Endo), FRACP (Endo), FRCP (Glas) (EDIN)
Deputy Chairperson
Secretary, Ethics Committee, IRB
Additional Vice Principal (Research)

Dr. Bobby John	MBBS, MD, DM, Ph D, MAMS	Professor, Cardiology, CMCH.	Internal, Clinician
Dr. Ashok Chacko	MD, DM, FRCP, FRCPG,FIMSA, FAMS	Director, Institute of Gastroenterology and Liver Disease, Madras Medical Mission, Chennai	External, Clinician
Mr. Samuel Abraham	MA, PGDBA, PGDPM, M. Phil, BL.	Sr. Legal Officer, CMCH.	Internal, Legal Expert
Dr. Vathsala Sadan	M.Sc, PhD	Professor, Community Hea Nursing, CMCH.	Internal, Nurse
Mr. Joseph Devaraj	B. Sc, BD	Chaplaincy Department, CMCH.	Internal, Social Scientist
Mr. C. Sampath	B. Sc, BL	Legal Expert, Vellore	External, Legal Expert
Mrs. Amala Ranjan	M Sc, RN, RM	Professor, Medical Nursing, CMC	Internal, Nurse
Mrs. Pattabiraman	B. Sc, DSSA	Social Worker, Vellore	External, Lay Person
Dr. Nihal Thomas	MD MNAMS DNB (Endo)FRACP (Endo) FRCP(Edin), (Glasg)	Secretary IRB (EC)& Dy. Chairperson (IRB), Professor of Endocrinology & Addl. Vice Principal (Research), CMC.	Internal, Clinician

We approve the project to be conducted as presented.

The Institutional Ethics Committee expects to be informed about the progress of the project, any **adverse events** occurring in the course of the project, any **amendments in the protocol and the patient information / informed consent**. On completion of the study you are expected to submit a copy of the **final report.** Respective forms can be downloaded from the following link: http://172.16.11.136/Research/IRB Polices.html in the CMC Intranet and in the CMC website link address: http://www.cmch-vellore.edu/static/research/Index.html.

Ethics Committee Blue, Office of Research, 1st Floor, Carman Block, Christian Medical College, Vellore, Tamil Nadu 632 002.
Tel : 0416 - 2284294, 2284202 Fax : 0416 - 2262788, 2284481 E-mail : research@cmcvellore.ac.in

OFFICE OF RESEARCH
INSTITUTIONAL REVIEW BOARD (IRB)
CHRISTIAN MEDICAL COLLEGE, VELLORE, INDIA.

Dr. B.J. Prashantham, M.A., M.A., Dr. Min (Clinical)
Director, Christian Counseling Center,
Chairperson, Ethics Committee.

Dr. Alfred Job Daniel, D Ortho, MS Ortho, DNB Ortho
Chairperson, Research Committee & Principal

Dr. Nihal Thomas,
MD., MNAMS., DNB (Endo), FRACP (Endo), FRCP (Glas) (EDIN)
Deputy Chairperson
Secretary, Ethics Committee, IRB
Additional Vice Principal (Research)

Fluid Grant Allocation:

A sum of 25,000/- INR (Rupees Twenty Five Thousand only) will be granted for 1 year.

Yours sincerely

Dr. Nihal Thomas
Secretary (Ethics Committee)
Institutional Review Board

Dr. NIHAL THOMAS
MD.,MNAMS.,DNB(Endo),FRACP(Endo),FRCP(Edin),FRCP(Glasg)
SECRETARY - (ETHICS COMMITTEE)
Institutional Review Board,
Christian Medical College, Vellore - 632 002.

CC: Dr. Vinod Joseph Abraham, Community Health, CMC.